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# Sociocultural Factors Influencing Cervical Cancer Prevention and Control Behaviors in Cusco, Peru

Venice Elizabeth Haynes

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SOCIOCULTURAL FACTORS INFLUENCING CERVICAL CANCER PREVENTION  
AND CONTROL BEHAVIORS IN CUSCO, PERU

by

Venice Elizabeth Haynes

Bachelor of Science  
Tennessee State University, 2003

Master of Science in Public Health  
Meharry Medical College, 2009

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Accepted by:

Heather M. Brandt, Major Professor

Daniela B. Friedman, Committee Member

David Simmons, Committee Member

Daron Ferris, Committee Member

Cheryl L. Addy, Vice Provost and Dean of the Graduate School

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“For I know the plans I have for you, plans to prosper you and not harm you. To give you a hope and a future” Jeremiah 29:11. To my Lord and Savior Jesus Christ who has kept me through this journey and guided my every step I am humbly grateful for the opportunity that you have given me to do this work. Mom and Dad, you have prayed me through, and it has finally come to pass. I appreciate you more than words can express. Corrie, you are the best sister a girl could have. Thank you for being my sounding board and comic relief. Dr. Brandt, I am unable to articulate how grateful I am for all that you have poured into me over the last four years. I have learned so much from you and I hope this is only the beginning of a career long relationship.

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## ABSTRACT

Cervical cancer is one of the most preventable types of cancer; however, it continues to pose significant health challenges for women in low and middle-income countries (LMICs), particularly in Peru. Studies previously conducted in Peru have examined factors associated with cervical cancer screening, screening access, availability, and geographical determinants on cervical cancer incidence and mortality. These studies have suggested the need to explore sociocultural factors and the roles of men and women in screening decisions associated with excessive cervical cancer burden and low rates of screening among Peruvian women. The goal of the dissertation research was to explore influences of sociocultural factors on cervical cancer prevention and control among women and men in Cusco, Peru. The specific aims were: 1) to explore the influences of cultural beliefs and the *marianismo-machismo* gender ideologies on cervical cancer screening, and 2) to identify preferences for health communication channels to increase cervical cancer prevention and control behaviors among women and men in urban and rural areas of Cusco, Peru. A qualitative approach was used to elucidate root social causes related to the lack of cervical cancer prevention and control. Semi-structured interviews were conducted with women (n=20), men (n=13), and clinicians (n=6) across urban and rural communities of Cusco. Six themes related to cultural beliefs emerged: 1) the purpose of the Pap test, 2) causes of cervical cancer, 3) fear, 4) embarrassment caused by Pap tests, 5) community conversations about Pap tests and cervical cancer, and 6) willingness to talk about cervical cancer. Six themes related to gender dynamics

emerged: 1) men's knowledge about the Pap test and cervical cancer, 2) men's attitudes toward the Pap test, 3) gender preference for the exam, 4) *machismo*, 5) *marianismo*, and 6) spousal support. Four categories of themes related to health communication emerged: 1) knowledge of HPV, the Pap test, and cervical cancer; 2) preference for communication channels, 3) interpersonal communication, and 4) preferred message content about cervical cancer. Findings suggested that cultural misconceptions about the Pap test and causes of cervical cancer influenced cervical cancer screening uptake primarily in the rural areas of the Cusco, Peru. Findings also suggested that male perspectives in rural communities played a large role in women's participation in cervical cancer screening. In an effort to increase knowledge about HPV, the Pap test, and cervical cancer, communication channels to disseminate information were primarily through physicians or through some process of interpersonal communication. There is an overwhelming need for interventions addressing sociocultural influences on cervical cancer throughout Cusco, Peru particularly because male perspectives play a large role in cervical cancer screening decision making among women in this area. Current and future health communication interventions about HPV, Pap tests, and cervical cancer should be culturally tailored and relevant for both women and men in efforts to reduce the cervical cancer disparity in Cusco, Peru.

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# CHAPTER 1

## INTRODUCTION

Cervical cancer is one of the most preventable types of cancer; however, it continues to be a significant health challenge for women in low and middle-income countries (LMICs), particularly in Latin America and Peru (Aguilar et al., 2016). Despite a decrease in incidence and mortality over the last 10 years, cervical cancer continues to pose a significant threat to women throughout the Peruvian region (Bray et al., 2018; Jacques Ferlay et al., 2010). As of 2018, cervical cancer was the second leading cause of cancer deaths among women and the second most commonly diagnosed cancer among women aged 15-44 (Bruni et al., 2018). Currently, approximately 11.8 million women in Peru are at risk for developing cervical cancer (Bruni et al., 2018). Cervical cytology, more commonly known and referred to in the dissertation research as the Pap test, has been a significant challenge for women in Peru and has contributed to the disparities among women in this region compared to other parts of the world (Aguilar et al., 2016).

Studies conducted previously in this region have examined the issues of access, availability, and geographical determinants of cervical cancer incidence and mortality with most concluding that differences in cancer outcomes are related to access to screening and treatment services (Agurto, Bishop, Sánchez, Betancourt, & Robles, 2004a; Almonte et al., 2011; Bychkovsky et al., 2016; Curado & de Souza, 2014; D’Orazio, Taylor-Ford, & Meyerowitz, 2014; Luque, Maupin, Ferris, & Condorhuaman, 2016). These findings also suggest there is an increasing need to explore the sociocultural

factors associated with excessive cervical cancer burden and low rates of screening among Peruvian women. Understanding gender roles of men and women in screening decisions and the sociocultural context of Peruvian life also have been recommendations for next steps to inform contextually and culturally appropriate cervical cancer interventions (Diaz et al., 2015; Gomez et al., 2015; Weaver, Geiger, Lu, & Case, 2013; Williams-Brennan, Gastaldo, Cole, & Paszat, 2012).

Broadly defined, culture is a set of ideals mutually agreed upon and adopted by a group of people, that shape world views and social norms throughout the life course (Kagawa Singer, Dressler, & George, 2016; Kagawa-Singer, Valdez Dadia, Yu, & Surbone, 2010). More specifically, culture incorporates elements of environment, economy, technology, religion, language, social structure, and beliefs and values (D’Orazio et al., 2014; Kagawa Singer et al., 2016; Kagawa-Singer et al., 2010). Understanding the cultural context and the variation that occurs within and between cultural groups is necessary to attempt to fully understand the origins of health disparities. Closer examination of social structures within a culture (i.e. sociocultural constructs), including but not limited to belief systems, customs, and gender roles, can provide clues to disparities in cervical cancer prevention and control behaviors. For this study, cervical cancer prevention and control behaviors include HPV vaccination, Pap test screening, follow-up, and diagnostic care.

During my time conducting preliminary studies of the social and environmental landscape of cervical cancer in Cusco, Peru, three salient issues were observed that warranted more exploration: 1) misconceptions about causes of cervical cancer, 2) stigma related to getting screened for or having cervical cancer, and 3) gender norms that

impede screening and prevention practices. Given these observations and the need to address the cervical cancer burden in this area, I have expanded on these three issues for the dissertation research.

### **Specific Aims**

The goal of the dissertation research was to explore the sociocultural influences on cervical cancer prevention and control behaviors among women residing in urban and rural areas of Cusco, Peru. To achieve the overall goal, the specific aims were:

1) To explore the influences of cultural beliefs, stigma, and *marianismo-machismo* gender ideologies on cervical cancer prevention and control behaviors among women and men in urban and rural areas of Cusco, Peru. More specifically, three primary topics were explored in detail: 1) cultural beliefs and practices that may exist among women related to cervical cancer, 2) the role of stigma related to HPV and cervical cancer and its impact on cervical cancer screening behaviors, and 3) assessing the presence of the *marianismo-machismo* gender ideology and its impact on cervical cancer screening behaviors of women in urban and rural areas of Cusco, Peru. Understanding the role of these sociocultural influences on cervical cancer prevention and control behaviors will provide key insight to inform the development of culturally-tailored interventions and health communication for Cuscanian women and men.

2) To identify preferences for health communication channels to increase cervical cancer prevention and control behaviors among women and men in urban and rural areas of Cusco, Peru. Aim 2 also used a qualitative approach to understand the preferred channel(s) for cervical cancer educational materials that are both culturally appropriate and feasible based on the availability of local resources. Participants provided

information on preferred channels and content of messages to increase general cervical cancer knowledge.

This research has the potential to advance knowledge and understanding of cancer prevention and control behaviors by incorporating the perspectives of men in understanding how cervical cancer affects men and women and using a sociocultural approach to account for the beliefs, stigma, and gender ideologies associated with the transmission, treatment, and survival of cervical cancer. Exploring differences in perspectives between urban and rural populations may yield additional insight on how to address cervical cancer screening behaviors within specific subgroups as opposed to generalizing findings to specific cultures and populations. Additionally, this study provides an in-depth perspective on the underlying causes of the disparities in cervical cancer prevention and control in this region compared to those in more developed countries and offers various communication strategies that can be used to address these disparities.

### **Preliminary Work**

Several personal and professional experiences have informed my dissertation research. Before coming to South Carolina, I conducted HPV and cervical cancer research with African American and Latina populations beginning in 2009. I have since conducted qualitative studies with African American males and females and have incorporated community-based participatory research (CBPR) and community engagement strategies within most of my research experiences. A majority of my research experience has been with qualitative data, and I have used this methodology in a variety of settings including faith-based and community focus groups and in one-on-one interviews.

Two specific research experiences as a doctoral student contributed to my dissertation research. Preliminary work on this project began with a federally-funded diversity supplement; Social and Physical Environmental Determinants of Intervention Sustainability funded by the National Institutes of Health, National Heart, Lung, and Blood Institute (NIH/NHLBI Grant # 3R01HL122285-03S1). This project allowed me to investigate the social and physical environments of participants completing a diet and physical activity intervention among African Americans in the southeastern United States (U.S.). From this, I gained experience in observing and gathering information about social, cultural, and physical factors that influence health behaviors in a variety of settings, expanded on mixed methods approaches, and the management of a research project from conception to completion.

In an effort to expand my work in social determinants of health and cervical cancer disparities, I spent four weeks in Cusco, Peru during the summer of 2017 through a study abroad program organized by the USC School of Medicine and CerviCusco. CerviCusco is a non-profit organization founded by Dr. Daron Ferris, based in Cusco, Peru to provide Pap tests to low income and indigenous populations in and around urban and rural areas throughout the region. Established in 2008, CerviCusco has provided Pap tests to approximately 10,000 women each year and is the only clinic that provides liquid-based cytology in the Andes region of Peru (“Cervi Cusco,” n.d.; Luque, Maupin, et al., 2016). During my time abroad, I was able to observe the existing health communication activities that were either currently in place or presented opportunities for improvement and/or intervention. In addition to these findings, observations and conversations exposed a number of sociocultural factors related to cultural identity,

empowerment, and relationships that required further exploration for how Peruvians understand and prevent cervical cancer in their community.

As a result of my time in Cusco, I was able to establish meaningful relationships with the CerviCusco clinic staff and surrounding community members. The relationships formed with the staff eased my return to Cusco for data collection for the dissertation project in the summer of 2018. Additionally, working with the clinic allowed for access to indigenous populations through mobile campaigns and was advantageous in that it expanded the reach to isolated groups and allowed for opinions to be gathered across regions that might not have otherwise been accessed.

### **Dissertation Preview**

The subsequent chapters of this dissertation cover the background of the cervical cancer burden in South America, and more specifically in Peru; describe previous research throughout the Peruvian region; and identify the gaps that this dissertation research aimed to address. The third chapter details the specific methods used to achieve the stated aims, including sampling and recruitment, instrument development, data collection, data analysis, and synthesis of the data. Chapter four includes three manuscripts describing the findings from the study as related to: 1) the role of culture on cervical cancer screening uptake (Aim 1); 2) the gender dynamics that impede or inhibit cervical cancer screening throughout parts of Cusco, Peru (Aim 1); 3) the preferences for health communication channels to disseminate information about HPV and cervical cancer throughout the region (Aim 2). The final chapter discusses all of the findings of the dissertation work and provides some insight into implications for public health practice and future directions.



## CHAPTER 2

### LITERATURE REVIEW

#### **Statement of Purpose**

The following section describes the burden of cervical cancer, cervical cancer prevention and control, and the comparison of cervical cancer screening recommendations and screening practices between Peru and the U.S. Additionally, this chapter will cover what is involved in cervical cancer prevention as it relates to screening and HPV vaccination, and the comparison of recommendations and screening practices of Peru to the U.S. The subsequent three sections will discuss findings from the literature related to cultural and societal beliefs, stigma, and gender roles as they relate to cervical cancer in Peru and will transition to the use of health communication channels to address cervical cancer prevention practices. In the discussion about communication channels, interpersonal communication will be highlighted as a specific channel to facilitate cervical cancer education particularly among indigenous groups. The section will conclude with research gaps, the significance and innovation of the dissertation to fill those gaps, and the theoretical framework that underlies the dissertation work.

#### **Burden of HPV and cervical cancer**

Human papillomavirus (HPV) is one of the most common sexually transmitted infections (STIs) and is linked to over 90% of cervical cancer cases globally (Bruni et al., 2017; Centers for Disease Control and Prevention, 2018). The Papanicolaou (Pap) test,

HPV DNA testing, and the HPV vaccine for cervical cancer prevention has resulted in dramatic decreases in incidence and mortality the U.S. The same decreases in cervical cancer incidence and mortality, however, have not been experienced in developing countries. In 2012, cervical cancer was ranked the fourth most common cancer in women worldwide, with close to 85% of incident cases and 87% of cervical cancer deaths occurring in developing countries (Ferlay et al., 2015; Torre et al., 2015). South American countries, which include Bolivia, Brazil, Chile, Colombia, Ecuador, French Guiana, Paraguay, Peru, Uruguay, and Venezuela, are considered low- and middle-income countries where, as of 2018, cervical cancer incidence ranges from 12.2 cases per 100,000 (Brazil and Chile) to 38.5 cases per 100,000 (Bolivia) (Ferlay et al., 2018; The World Bank, n.d.). Also as of 2018, cervical cancer is excessively high in Peru where the incidence rate is 23.2 cases per 100,000, which is more than four times higher than in the U.S. (6.5 cases per 100,000), and nearly double the worldwide incidence rate of 13.1 cases per 100,000 (Bray et al., 2018; National Cancer Institute, n.d.). The mortality rate in 2018 for cervical cancer in Peru is 10.2 cases per 100,000, which is nearly five times higher than in the U.S. (1.9 deaths per 100,000), and nearly double the worldwide mortality rate of 6.9 deaths per 100,000 (Bray et al., 2018; National Cancer Institute, n.d.). In Peru, men experience genital HPV at higher rates than women experience cervical HPV infection in women which suggests that persistence of HPV is less in men than it is in women (Bruni et al., 2018). Cervical cancer poses a significant burden on the health and lives of Peruvian women, their families, and society.

## **Risk factors for cervical cancer**

HPV is a necessary but insufficient risk factor for the development of cervical cancer. HPV infection acquired through sexual activity is the primary cause of cervical cancer. Having multiple sex partners can increase the likelihood of contracting HPV. Likewise, having more than three full term pregnancies or being on birth control for periods longer than five years all increase the risk for developing cervical cancer. Other risk factors include low fruit and vegetable intake, being overweight, and smoking (American Cancer Society, n.d.; Bruni et al., 2018; Division of Cancer Prevention and Control, n.d.; Kessler, 2017).

## **Cervical cancer screening recommendations in the U.S. and Peru**

Cervical cancer screening was first introduced in the U.S. in the 1950s. Since then, there has been an approximately 60% decrease in cervical cancer mortality in the U.S. Screening guidelines have evolved as new technologies for screening have been introduced, and there is improved understanding of the natural history of cervical cancer, such as the discovery of HPV as a main cause of cervical cancer (Guido, 2018; National Cancer Institute, 2013; Sawaya & Huchko, 2017). The current U.S. guidelines recommended by the U.S. Prevention Services Task Force (USPSTF) are to begin Pap test with cytology at age 21 and every three years until age 30 (U.S. Preventive Services Task Force, 2018). A screening period of five years is recommended for women age 30 to 65 who get a Pap test with cytology in combination with an HPV DNA test and are found negative for HPV (U.S. Preventive Services Task Force, 2016). It is currently not recommended to continue with a Pap test for women over the age of 65 or women that have undergone a total hysterectomy (U.S. Preventive Services Task Force, 2016). Over

the last 10 years, there has been a downward trend in cervical cancer screening in the U.S. with 81% of age-eligible women adhering to current screening recommendations (Centers for Disease Control and Prevention (CDC), 2013; Morère et al., 2018; Smith et al., 2017; D. X. Yang, Soulos, Davis, Gross, & Yu, 2018; Yoo et al., 2017). Cervical cancer screening has been largely well accepted in the U.S. and has saved lives.

In Peru, the average age of first sexual encounter for females is 18 and 17 for males, and the average age at marriage is 23 for females and 27 for males (Bruni et al., 2018). Despite these ages of sexual encounters, the 2010 Cancer Profile for Peru, screening recommendations for Peruvian women are that a Pap test should be conducted among women aged 30-49 annually (Bruni et al., 2017; RINC/UNASUR, 2012). Specific screening methodology recommendations for Peru can be found in Table 2.1. There have been inconsistencies in reports of cervical cancer screening rates due to regional variations and accessibility to screening throughout the country (Bychkovsky et al., 2016; Liebermann, VanDevanter, Hammer, & Fu, 2018; Murillo et al., 2008; Paz-Soldán, Bayer, Nussbaum, & Cabrera, 2012; Torre et al., 2015). The most recent 2018 reports indicate that between 52-67% of women between the ages of 30 and 59 have received a Pap test within the last five years (Bruni et al., 2018; Liebermann et al., 2018). Inconsistencies in screening recommendations and reporting of those recommendations has contributed to lower screening uptake in Peru compared to the U.S.

**Table 2.1. Cervical cancer screening recommendations in Peru and the U.S.**

	Age	Recommendation	Screening Coverage
Peru <sup>1</sup>	30 - 49	Cytology screening or VIA every 2-3 years	52-67%
U.S. <sup>2,3</sup>	21 – 29	Cytology screening every 3 years	81%
	30 – 64	Cytology + HPV DNA co testing every 5yrs*	
	65+	Not recommended	

\* when Pap test is normal

<sup>1</sup> Recommendation per the Peruvian Ministry of Health; does not include opportunistic screening.

**Citation:** Bruni L, Albero G, Serrano B, Mena M, Gómez D, Muñoz J, Bosch FX, de Sanjosé S. (2018). ICO/IARC Information Centre on HPV and Cancer (HPV Information Centre). Human papillomavirus and related diseases in the world. *Summary Report*.

<sup>2</sup> Recommendation per the US Preventive Services Taskforce (USPTSF) as of 2018.

**Citation:** *Final Update Summary: Cervical Cancer: Screening*. U.S. Preventive Services Task Force. August 2018.  
<https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/cervical-cancer-screening2>

<sup>3</sup> **Citation:** Watson, M., Benard, V., King, J., Crawford, A., & Saraiya, M. (2017). National assessment of HPV and Pap tests: changes in cervical cancer screening, National Health Interview Survey. *Preventive Medicine*, 100, 243-247.

## Clinical procedures

Cervical cancer screening involves a Pap test with cytology, and a resolution of the test (i.e. normal or abnormal). If an initial test shows normal results, routine screening intervals are recommended. If results are abnormal, the recommendation for follow-up care is a colposcopy within 12 months to determine if the abnormality is pre-cancerous, cancerous, or atypical squamous cells of undetermined significance (ASC-US) (“ASCCP Guidelines - ASCCP,” n.d.). In the U.S., current rates of abnormal tests are difficult to

ascertain. Estimates indicate that approximately 10-15% of all Pap tests conducted each year are abnormal in the U.S. (Centers for Disease Control and Prevention (CDC), 2013; Fowler et al., 2017). In Peru, abnormal Pap tests are missed more often due to the capacity and resources of physicians to properly perform and interpret cytology, and the compromised sensitivity and specificity of testing with visual inspection with acetic acid (VIA) (Bychkovsky et al., 2016; Murillo et al., 2008; Paz-Soldán, Nussbaum, Bayer, & Cabrera, 2010). A 2015 report released on the epidemiology of cervical cancer in Latin America, found an inverse relationship between the coverage in cytology testing and cervical cancer mortality rates (Capote Negrin, 2015). For example, using the U.S. as a benchmark; in 2015, there was 80% coverage for cytology-based testing and a mortality rate of 2.3 deaths per 100,000 whereas Peru reports approximately 50% coverage for cytology and a mortality rate of 12.2 deaths per 100,000 (American Cancer Society, n.d.; Capote Negrin, 2015).

### **HPV vaccination in the U.S. and Peru**

The first quadrivalent vaccine to prevent HPV and HPV-related cancers and diseases was licensed by the FDA in 2006 and subsequently recommended in the U.S. (Centers for Disease Control and Prevention (CDC), 2010; Markowitz et al., 2007). Current recommendations for HPV vaccination in the U.S. are for males and females aged 9-26 with some conditions (Meites, 2016) (Table 2.2). The nonavalent vaccine was released in 2016 to guard against the same four HPV types as the quadrivalent vaccine, plus five additional types that cause other HPV-related cancers (Markowitz, Gee, Chesson, & Stokley, 2018). Current rates of HPV vaccination uptake in the U.S. as of

2017, were approximately 66% for 3 doses including males and females between 13-17 years, and 49% up-to-date (UTD) vaccination among the same gender and age group (respectively) (Bruni et al., 2017; Walker, 2017). The UTD vaccination recommendation means that all three doses of the vaccine have been received if between the ages of 15 and 17, or 2 doses have been received if vaccinated before the age of 15 as of December 2016 (Walker 2017). In 2016, HPV vaccine uptake for adults aged 19-26 was reported to 49% for at least one dose, with high variation by geographic location and other sociodemographic characteristics (Walker, 2017). The quadrivalent HPV vaccine was introduced in Peru in 2011 for girls starting at age nine with three doses required (Bruni et al., 2017). In 2016, a two-dose schedule of the quadrivalent vaccine was recommended for girls aged 9 -15 (Bruni et al., 2017). Catch-up vaccination is a term used for vaccinating within the age range but after the after the recommended age of beginning vaccination. Catch-up vaccination is recommended for females and some males aged 15 to 26 (Meites, 2016). Catch-up vaccination recommendations for Peru has not been well documented (Bruni et al., 2018, 2017).

Overall, there is a significant burden of cervical cancer in Peru compared to the U.S., which is consistent with the substandard screening and prevention practices throughout the region. Several issues contribute to the lack of efficiency in screening to reduce the incidence and mortality of cervical cancer in Peru. As such, there is great potential for a variety of interventions to address the behavioral barriers to screening uptake in this region particularly with an increased understanding in attitudes, cultural beliefs, and societal influences that may compound existing structural barriers toward prevention and control behaviors like screening and vaccination.

## **The cervical cancer landscape in Peru**

In 2007, a partnership between the Ministry of Health and the Instituto Nacional de Enfermedades Neoplasias (INEN) was formed to develop Peru's first comprehensive cancer control plan with the goal to improve services related to cancer care to address the high incidence of cervical, breast, stomach, lung, and prostate cancers in Peru. This plan incorporated a universal insurance plan to ensure that the poorest communities that were experiencing cancer were able to receive treatment.

Over time, the plan developed into "Plan Esperanza" or the Hope Plan (Aguilar et al., 2016; Vallejos, 2013). In 2012, Plan Esperanza was expanded and by 2014, was able to provide >2.3 million Pap tests to women in Peru (Aguilar et al., 2016). Despite the availability of these services, disparities in cervical cancer were still observed between regions. As of 2016, Plan Esperanza was in place but had yet to be revised. Peru had established population-based cancer registries in Lima, Arequipa, but were lacking in quality and accuracy of data collection and reporting. Collectively, these registries only cover 33% of the population of Peru which suggested that there was a significant portion of the cancer incidence and mortality reporting in Peru that was being missed (Piñeros et al., 2017). Additionally, there was no formal early detection program (Piñeros et al., 2017). By 2017, a meeting was convened to address the impending disparities and to develop recommendations to increase evidence-based programming, improved and increased continuity of care programs, to build and sustain community buy in for these programs (Mendoza-Cervantes et al., 2017). The current plan is currently being revised to prioritize children's leukemias, breast, and cervical cancers (Piñeros et al., 2017).



**Table 2.2 Vaccination recommendations for Peru and the U.S.**

	<b>Peru<sup>1</sup></b>	<b>U.S.<sup>2</sup></b>
<b>Year introduced</b>	2011	2006
<b>Vaccination age</b>	9 – 15	9 – 26*
<b># of doses</b>	2 if age < 15	2 if age <15 3 if age 15 – 26
<b>Gender recommendation</b>	Females	Females + Males**
<b>Catch-up vaccination ages</b>	-	Age 15-26
<sup>1</sup> Peru Ministry of Health 2014 - Ministerio de Salud de Perú. Este año se fortalece la inmunización contra el virus papiloma humano [Internet]. 2013. Available from: <a href="http://www.minsa.gob.pe/portada/prensa/nota_completa.asp?nota=12803">http://www.minsa.gob.pe/portada/prensa/nota_completa.asp?nota=12803</a>		
<sup>2</sup> Meites E, Kempe A, Markowitz LE. Use of a 2-Dose Schedule for Human Papillomavirus Vaccination — Updated Recommendations of the Advisory Committee on Immunization Practices. MMWR Morb Mortal Wkly Rep 2016;65:1405–1408. DOI: <a href="http://dx.doi.org/10.15585/mmwr.mm6549a5">http://dx.doi.org/10.15585/mmwr.mm6549a5</a>		
* Can begin as early as age 9 otherwise recommendation is to begin at age 11-12 ** Males aged 22-26 recommended if having sex with another male and not previously vaccinated		

Consideration was given to the economic impact of HPV vaccination in young girls as part of an existing cervical cancer screening program in Peru (Goldie et al., 2012). Models looking at the benefit, value, and affordability of screening in adult women to be associated with a 12% reduction in lifetime risk for cervical cancer with the lowest levels of screening and the vaccination of adolescent girls likewise contributed to a 46% reduction in risk for cervical cancer (Goldie et al., 2012). Collectively, these two methods were found to be cost effective and contribute to two out of every three cervical cancer deaths in Peru (Goldie et al., 2012). By 2016, a school-based HPV vaccination program was instituted by the Peruvian Ministry of Health for adolescent girls with

approval from parents, however, no formal early detection program has been instituted, despite the resources identified in Plan Esperanza (Piñeros et al., 2017).

### **Empirical studies and interventions**

In a randomized control trial of participants with STIs, analysis was performed on a sample of women to determine the profile of women that receive a Pap test in urban communities in Peru. Women within the sample that had at least one child, were between the ages of 25 and 29, had at least a secondary education, was sexually active at an early age, had symptoms such as vaginal discharge within the past year, and lived on the coast were significantly more likely to have had a Pap test than women who did not meet these criteria (Paz Soldan et al., 2008). In 2013, Barrionuevo-Rosas et al. did a similar analysis that examined the type of insurance held by women in Peru as a predictor of Pap test screening uptake in addition to other socioeconomic variables. Findings from this study were similar to that of Paz Soldan (2008) in that 63% of women that were sexually active, were older (between the ages of 30 and 49), and had public or private insurance had had a Pap test in the last five years compared to women that only had a primary education, had a lower SES, spoke an indigenous language, lived in a rural area, and had no insurance who were less likely to have been screened (Barrionuevo-Rosas, Palència, & Borrell, 2013).

Similar to the profile of women who get screened for cervical cancer, one study looked at risk factors of women in the Amazonian region of Peru for high risk HPV (HR-HPV) and the association with high-grade cervical lesions (CIN 2+) (Almonte et al., 2011). The profile of women with HR-HPV and cervical intraepithelial lesions (CIN) 2+

were similar to women profiled in other studies for Pap test screening. Early age at first intercourse, multiple sex partners, having little to no education, and having at least three pregnancies were all significantly associated with having HR-HPV (Almonte et al., 2011). There was also a significant association found with women that had more pregnancies being more at risk for CIN2+ than HR-HPV. These findings were mostly found in women less than the age of 40 (Almonte et al., 2011).

In 2008, the TATI project (TATI is the Spanish acronym for *tamizaje y tratamiento inmediato* meaning screening and immediate treatment) was a large-scale service delivery project initiated by the Peruvian Ministry of Health to increase cervical cancer screening uptake from November 2000 to October 2003 (Luciani & Winkler, 2006; Robles et al., 2009; Winkler, Bingham, Coffey, & Handwerker, 2008). Activities included health education sessions via community events and home visits that covered body awareness, early detection, locating services, and self-esteem education. The target number of eligible women to be screened through the project was 80%, however, only 32.3% were actually screened. Several factors such as clinician availability, communicable outbreaks, and competing health issues were cited as some reasons for the low uptake. Additionally, the lack of an evaluation component and interviewing women not screened impeded further understanding of lack of participation (Luciani & Winkler, 2006; Robles et al., 2009).

As part of the TATI project, Winkler and colleagues aimed to investigate why screening uptake had not increased as a result of participating in educational outreach (Winkler et al., 2008). The significant predictors in this study showed that screened women had higher education, wealth, and a supportive male husband or male partner

compared to women who had not been screened and had less education, were poorer, and did not have a supportive husband or male partner. Similarly, women who had not been screened were more likely to believe or have a husband believe that screening was an evil or harmful practice and know less women that had not been screened compared to screened women who knew more women that had been screened (Winkler et al., 2008). This study emphasized the need for more information to be gathered from women who have never been screened in order to address a number of factors including sociocultural influences on cervical cancer screening uptake (Winkler et al., 2008).

The PERCAPS study (PERU Cervical Cancer Prevention Study) took a CBPR approach to training community health leaders to recruit for vaccination, screening and treating mothers and daughters for HPV and cervical cancer (Abuelo et al., 2014). This work built upon a similar model in Manchay, Peru and attempted to expand to another geographically challenged area (Iquitos) to determine similar success. The authors hypothesized that using a CBPR approach would free up resources for clinicians to treat women that were HPV positive (Abuelo et al., 2014). Findings revealed that modifications needed to be made from the mother-daughter dyad to female-minor dyads as they were found to be more realistic and feasible in the area. Some cultural issues of note were that the CBPR approach was more accepted in rural areas than urban. The CBPR approach was found to be successful overall and even more so when used in tandem with a school-based vaccination program (Abuelo et al., 2014).

In an effort to address the geographical access to screening barrier, the Día del Mercado Project implemented a mobile clinic model bringing Pap test services to rural area markets (Ferris, Shapiro, et al., 2015). In an evaluation of this method, women

seeking services or in local markets where the mobile clinics took place were surveyed about their barriers to seeking Pap tests, what they knew about the Pap test and cervical cancer, and their thoughts about the mobile services provided in their local areas. A significant number of women were pleased with the option to receive a Pap test close to their home compared to women that sought treatment in a clinic (Ferris, Shapiro, et al., 2015).

### **Barriers to cervical cancer prevention and control in Peru**

A number of barriers to cervical cancer screening have been identified in various studies over the last decade which have been geographical, structural, infrastructural, procedural, and cultural in nature. Paz-Soldan identified a number of structural barriers to cervical cancer screening in the form of quality service delivery, availability of appropriate resources, physician and clinic capacity, and consistency with processing results (Paul et al., 2013; Paz-Soldán et al., 2012). Regional geographical disparities have been identified within Peru as the more populated areas along the coast have more access to specialists, clinics, and testing resources than those in remote areas (Aguilar et al., 2016). Educational and cultural differences have also posed additional challenges that have contributed to the cervical cancer disparities within country (Aguilar et al., 2016). Recommendations from these and other studies have suggested ongoing comprehensive approaches to include interventions across the spectrum of education, geography, culture, infrastructure, and training to continue to decrease the cervical cancer burden throughout the country (Murillo et al., 2008; Paul et al., 2013; Paz-Soldán et al., 2012).

Knowledge about HPV and cervical cancer have been studied extensively in Peru (Agurto, Bishop, Sánchez, Betancourt, & Robles, 2004b; Delgado, Menacho, Segura,

Roman, & Cabello, 2017; Han et al., 2012; Lee, Paz-Soldan, Carcamo, & Garcia, 2010; Liebermann et al., 2018; Luque, Maupin, et al., 2016; Paz-Soldán et al., 2010). In the case of cervical cancer, having limited knowledge about a disease lends itself to misconceptions and in turn become commonly held beliefs (Paz-Soldán et al., 2010). Misconceptions most commonly mentioned in the literature include improper hygiene, having one or too many abortions, genetic susceptibility, promiscuity, and the use of birth control (Paz-Soldán et al., 2010). Additionally, some women believe that the purpose of a Pap test is to cure a fungus or bacterial infection, is a type of vaginal or female cleaning, or is used to diagnose a uterine cancer (Paz-Soldán et al., 2010). Regarding the Pap test itself, a common misconception is that it is painful and will be a traumatic experience (Paul et al., 2013; Paz-Soldán et al., 2010). Some women in this region believe that a Pap test is only required one time throughout their life, so they do not return for future visits (Paz-Soldán et al., 2010).

Researchers that have observed Peruvian culture as it relates to cervical cancer screening have identified the lack of prioritization for preventive healthcare practices, particularly with cervical cancer screening. This means that women tend to only visit a doctor or clinic when they experience symptoms and do not prioritize prevention practices for their health (Liebermann et al., 2018; Paz-Soldán et al., 2012; Winkler et al., 2008). Not prioritizing prevention practices such as getting a Pap test regularly has cultural implications that may factor into the high disparity of cervical cancer in Peru. While prevention is not a common practice, religion also plays a role in knowledge and screening practices. Catholicism is the principal religion among men and women in Peru, and they tend to lean toward conservative ideals for their families which means that

cervical cancer is not a topic that is widely discussed at home or as part of sex education in schools (Paz-Soldán et al., 2010). Other barriers to cervical cancer screening in Peru have been related to mistrust with the healthcare system, lack of spousal support, modesty, and embarrassment exposing genitals to a male physician (Agurto et al., 2004a; Luque, Maupin, et al., 2016; Paul et al., 2013; Paz-Soldán et al., 2010). Other findings related to cultural and cervical cancer in Peru have included the preferences and practices of traditional medicine, indigenous healers or ‘*curanderos*’ and using home remedies to self-treat at the presence of cancer symptoms, (Granda-Cameron, 1999; Luque, Maupin, et al., 2016; Paz Soldan et al., 2008) while other women view going to the doctor to get checked for cancerous lesions as a death sentence (Agurto et al., 2004a; Luque, Maupin, et al., 2016; Paul et al., 2013; Paz Soldan et al., 2008; Paz-Soldán et al., 2010). A number of studies have also cited familial priorities or *familismo* as reasons women do not get screened for cervical cancer (Agurto et al., 2004a; Arredondo, Pollak, & Costanzo, 2008; Luque, Maupin, et al., 2016; Paz Soldan et al., 2008; Paz-Soldán et al., 2010).

The studies previously outlined highlight the work that has happened in Peru to address the cervical cancer burden throughout the country using a variety of approaches to include qualitative, quantitative, and mixed methods to understand barriers. What was not prominent in these studies were the inclusion of the perspectives of men. Likewise, very few studies incorporated perspectives of clinicians, or made comparisons between perspectives of cervical cancer screening barriers between urban and rural populations. Also, not prominent in these studies was a deeper exploration of the impact of gender on screening behaviors or if cervical cancer is stigmatized within communities. This dissertation research will look at these factors on cervical cancer screening in more detail.

## Stigma

The definition of cultural stigma for the dissertation research is inspired by Link and Phelan (2001) and defined as the degree to which one or a group of individuals is set apart or made to feel “less than” if they present with a disease that is counter to the cultural or social expectations of the surrounding community (Link & Phelan, 2001). The degree to which disease-related stigma is understood varies greatly depending on a number of factors; 1) what is valued most in various cultures, 2) the way in which stigma is defined, conceptualized, and measured, and 3) the disease burden itself (Link & Phelan, 2001; L. H. Yang, Thornicroft, Alvarado, Vega, & Link, 2014). From the conceptualization standpoint, the approach to understanding stigma can be *emic* (i.e. from the person or social groups point of view) or *etic* (i.e. from the observer’s point of view) (Bhasin, 2007). As a result, two varying degrees of stigma concepts can be developed and consequently be contextually mischaracterized if only the etic perspective is used. Link and Phelan delineate the conceptualization of stigma identifying cultural beliefs as the mechanism that ultimately sets one group of people apart from another (Link & Phelan, 2001). Cultural beliefs are pivotal for how stigmatized diseases are understood because it could have everything to do with the roles that stigma plays out among a group of people. For example, Weiss et al. discusses how different cultures might assign meaning to certain diseases which could mean that having the symptoms of a disease may not be as bad as being associated with having the disease itself (Weiss, Ramakrishna, & Somma, 2006). Weiss and Yang also make the case for the need to understand how stigma manifests itself in different cultures, whether it be self-perceived or enacted stigma,



(Daley et al., 2010; Dyer, 2010) or through delayed or avoidance of treatment and prevention (Oaten, Stevenson, & Case, 2011; Weiss et al., 2006; L. H. Yang et al., 2014).

Cancer, in general, has been a stigmatized disease for many years while the same holds true for other STIs, such as HIV. Because HPV is an STI that is the cause of cervical cancer, there are many opportunities for stigma to develop. Dyer highlights the effects of cervical cancer survivorship and the self-perceived and enacted stigma that is associated with cancer survivorship as an outcome of “promiscuity” and irresponsible lifestyle choices (Daley et al., 2010; Dyer, 2010). As a result, cervical cancer becomes sexualized and changes the perception of risk for disease, the need to maintain social approval, and the abandonment of screening for fear of admitting to sexual relations to family, and community (D’Orazio et al., 2014; Teixeira, 2015; Wiesner-Ceballos, Vejarano-Velandia, Caicedo-Mera, Tovar-Murillo, & Cendales-Duarte, 2006). It is important to understand ‘what matters most’ in cultural stigma and how that might manifest as it relates to cervical cancer screening among women and men. Additionally, it will be important to note the differences in how cervical cancer screening might be stigmatized between married and single Peruvian women.

### **Gender ideologies**

In Latin America, the concept of *marianismo* is defined as the woman’s regard for purity, modesty, taking care of the home, childrearing and submissiveness to one’s husband; while *machismo* is considered to be an exertion of a masculinity, strength, pride, and the responsibility to protect and provide for his family (Castillo, Perez, Castillo, & Ghosheh, 2010; D’Orazio et al., 2014; Navarro, 2002). Together, the *marianismo-machismo* ideology is defined as patterns of gender norms in social and

intimate settings (D’Orazio et al., 2014). One premise of the *marianismo* concept is that a pure and virtuous woman need not be screened for something related to an STI because chaste women do not engage in activities that require these types of screenings. This underscores the gaps in knowledge about cervical cancer and screening practices which also makes messaging strategies difficult to resonate with women who hold this mindset (Ashing-Giwa et al., 2004; Flores & Bencomo, 2009). Similarly, the *machismo* concept can work against the perception of risk such that the idea of needing cervical screening would bring shame to the family, implying promiscuity of the female partner and impeding social status in the local Latino community (D’Orazio et al., 2014). Luque (2016) found that domestic violence and disapproval of wives seeing a male gynecologist was an issue in certain areas of Peru (Luque, Maupin, et al., 2016). These findings are consistent with observations of advertisements for domestic violence support for women in the same region. (unpublished data) Not all Latinx individuals uphold gender roles to the same degree (D’Orazio et al., 2014; Nuñez et al., 2016; J. B. Torres, Solberg, & Carlstrom, 2002), but it remains necessary to explore gender dynamics and the degree of their impact on cervical cancer screening decision-making and uptake. Contextually, men head the household, and women comply with their husbands’ decisions before seeking health services, particularly regarding cervical cancer screening (Erwin et al., 2010).

Other Latin American cultural constructs include *falismo*, and *hembrismo* which are extensions of femaleness, empowerment and the equality of relationships between men and women in a society (Castillo et al., 2010; D’Orazio et al., 2014; Navarro, 2002). Contrary to the culture of empowerment is *simpatia* which emphasizes the avoidance of conflict and maintaining harmony, *familismo* which prioritizes the family’s needs before

that of the female's desires and *respeto* which emphasizes social placement and the sexual silence females experience as to not negotiate sexual relations with the male partner (Ulibarri, Raj, & Amaro, 2012). Arredondo (2008) found that cultural constructs like those previously mentioned were significant predictors of cervical cancer screening uptake particularly among women that had never been screened and endorsed these cultural practices compared to those who did not and were more compliant with screening (Arredondo, Pollak, & Costanzo, 2008). Through empirical testing of the measures, these cultural constructs were all highly correlated with each other suggesting that when one construct was endorsed, all of the others were likewise endorsed (Elva Maria Arredondo et al., 2008). Erwin (2010) found similar findings in a qualitative study that identified that all Latina immigrant women identified the role of *machismo* in an existential or negative category as it relates to the PEN-3 domains of cultural empowerment and relationships and expectations (Erwin et al., 2010). PEN-3 is a cultural framework that accounts for the role of culture in the adoption of health behaviors and will be discussed in greater detail later in this work.

Studies that have addressed the role of the *machismo* gender ideology in various Latin American and immigrant populations have suggested the need to include men in educational campaigns related to sexual and reproductive health including cervical cancer (D'Orazio et al., 2014; Erwin et al., 2007). This also has implications for the development of cervical cancer screening messaging that plays to the traditional values held by Latinas while positioning screening in a positive frame for both men and women. Acknowledging the role of men in sexual health interventions is a means to break down one of the sociocultural barriers that impede cervical cancer screening. By involving men,

educational efforts can be bi-directional within male-female dyads thereby increasing the likelihood of approval of screening and prevention of both parties. Moreover, when men are involved in educational efforts to the same degree women are, they can change social norms, become a positive support system in the event of an unfortunate screening outcome, and a resource for a reminder to maintain regular screening uptake. Long term, this approach drives the screening rates up and the mortality from cervical cancer down.

### **Health communication channels**

Targeting screening behaviors by using communication channels to increase cervical cancer knowledge is important because of its potential to reach a broad audience either directly or indirectly and through information gathering practices that people already use in their daily lives, (TV, radio, magazines, billboards, posters, other people, etc.). Media channels are formally defined by Oetzel et al. as the mode for which a message is conveyed or the mechanism used for communicating the message (Oetzel, Vargas, Ginossar, & Sanchez, 2007). Media (e.g. TV, radio, newspapers, magazines, billboards, YouTube videos, and DVDs), and interpersonal communication (e.g. family, friends, physicians, social networks), are the channels referenced in this study. Lipkus discusses the importance of communicating risk in different formats such as numerical, visual, and verbal, and discusses the pros and cons of each highlighting the need to understand the priority populations demographics for maximum effectiveness (Lipkus, 2007). Schooler and colleagues similarly highlighted the tradeoffs of different media channels like those previously mentioned based on desired outcomes of reach, impact or specificity of an audience (Schooler, Chaffee, Flora, & Roser, 1998).

Media channels are important in health communication research because they can be used as a mechanism for which an intervention can be delivered to create behavior change. The Centers for Disease Control and Prevention's (CDC) Community Guide provides recommendations for communication channels and formats that have been shown in the literature to be effective ("Guide to Community Preventive Services. Cancer Screening: Mass Media Targeting Clients – Cervical Cancer," n.d.). An example of the application of this recommendation is the implementation of the *Inside Knowledge* Campaign by CDC for gynecologic cancer awareness in the U.S. (Centers for Disease Control and Prevention, n.d.; Rim, Polonec, Stewart, & Gelb, 2011). This campaign made use of both small and mass media channels in posters, and radio and video public service announcements respectively. These campaigns are important uses of the evidence of effectiveness for cervical cancer and other cancer awareness interventions across the U.S.

In 2009, Ferris and colleagues tested a cervical cancer educational video among Spanish and Quechua speaking women in the waiting areas of clinics (Ferris, 2009). At the completion of pre and post knowledge questionnaires, there was no change in knowledge about cervical cancer among Quechua speaking women but a significant change among Spanish speaking women (Ferris, 2009). Quechua is the predominant language in the rural Andes mountains, but it is not a written language making the dissemination of written cervical cancer information or information communicated in Spanish, difficult to understand. This dissertation research provided valuable information for how educational videos can be adapted for use in Quechua speaking populations in the Andes region. In a similar 2015 study, an informational video was tested with women scheduled to have a loop excision surgery for cervical abnormalities (Ferris,

Condorhuaman, Waller, & Lilienthal, 2015). Findings revealed that women who viewed the educational video were significantly calmer, content, and relaxed at post video and post-surgery, compared to baseline measures (Ferris, Condorhuaman, et al., 2015). This study is also an example of a culturally-tailored communication intervention for cervical cancer prevention and control.

### **Interpersonal communication**

The role of interpersonal communication as a mechanism for transferring information requires more examination. Berkman et al. 2000 highlights the role of social relationships on health outcomes and the importance of social capital, social ties, and social networks that should be embedded in a social cultural context to further understand how these constructs influence health (Berkman & Glass, 2000). Research has suggested that in the development of health communication campaigns, interpersonal communication should be considered equally with other channels for dissemination of health information (van den Putte, Yzer, Southwell, de Bruijn, & Willemsen, 2011).

Findings from studies that looked at interpersonal communication as a channel for cervical cancer and HPV information recognized the limitation of knowledge about cervical cancer screening and prevention in low- and middle-income countries (Ports, Reddy, & Rameshbabu, 2015). Researchers aimed to understand barriers women faced for getting screened and wanted to gather information about preferences for receiving health information about cervical cancer. Thirty in-depth interviews with women ages 18 to 46 to were conducted to solicit their preferences for information channels. Because cervical cancer knowledge was minimal, participants often commented that they would trust the information from interpersonal methods such as doctors and nurses (Ports et al.,

2015). While the findings could not be generalized to a larger population of women, nor were the logistics of such educational methods explored, this study took advantage of the depth of information gathered from a qualitative approach. Similarly, Friedman and Shepeard conducted 36 focus groups across the U.S. about knowledge and attitudes about HPV and the HPV vaccine and to gather preferences for receiving information on the topic. It was found that overall knowledge about HPV was low and that fear and anxiety were associated with knowing that a sexually transmitted disease could cause cancer. Consistent with other studies, participants were most likely to receive information from the internet and communication with healthcare professionals (Friedman & Shepeard, 2007). Similar findings came from a study conducted by Friedman and colleagues that suggested that interpersonal communication was the primary channel for seeking information about HPV and cervical cancer, specifically among healthcare providers (Friedman & Shepeard, 2007). Interpersonal communication is an important channel to deliver health information particularly among indigenous populations that may have a variety of educational needs.

In a study that observed patient provider communication in 185 total observations, Bayer and colleagues detail the number of opportunities for patient provider communication that were not employed (Bayer, Nussbaum, Cabrera, & Paz-Soldan, 2011). While physicians inquired about women's Pap test status, recommendations for screening and education about the importance of screening was absent during a majority of the conversations with patients. These findings indicate a need for not only recommendations to obtain a Pap test if overdue, but for expanded health education about the importance of the preventive screening practice (Bayer et al., 2011) Bayer 2011).

## **Research gaps**

Despite the studies that have been conducted to examine barriers to cervical cancer prevention and control in various Latin American countries including Peru, only some have explored sociocultural barriers specifically (Agurto et al., 2004a; D’Orazio et al., 2014; Erwin et al., 2010; Luque, Maupin, et al., 2016; Paz Soldan et al., 2008; Paz-Soldán et al., 2010). The inclusion of men’s perspectives in studies of cervical cancer prevention and control has been lacking. Because gender norms vary across different Latino groups and more research is needed to understand the degree to which this impacts cervical cancer screening practices in Latino subgroups (D’Orazio et al., 2014).

Furthermore, the cultural differences between urban and rural indigenous men and women as they relate to cervical cancer, and the role of gender dynamics within these populations have also not been extensively explored. In terms of methodological gaps, using a qualitative approach to understanding sociocultural influences on cervical cancer prevention have not been used extensively. In Peru specifically, few (Luque, Maupin, et al., 2016; Paz-Soldán et al., 2010) studies have been conducted qualitatively particularly in rural communities, to understand cervical cancer prevention in indigenous cultures despite the attempt to increase the availability of services. Only a small number of studies have been done to look at health communication as a method of intervention to improve cervical cancer control behaviors among Peruvian women (Ferris 2009, Ferris et al. 2015). Likewise, the involvement of men and women in the formative process of identifying viable health communication channels and preferences for health communication messages for cervical cancer education have not been explored in detail despite the call to involve men in the intervention and health education messages around HPV and cervical cancer (D’Orazio et al., 2014; Erwin et al., 2007). Turning the negative



aspects of cultural beliefs, stigma, and ideologies of *marianismo* and *machismo* into positive messaging has the potential for behavior change with a cultural foundation around cervical cancer prevention in Latinx populations. To my knowledge, the dissertation research was the first study to incorporate all of these aspects using only qualitative methods in Cusco, Peru.

### **Significance**

The dissertation research is significant in several ways. First, cervical cancer contributes to too many deaths given screening and vaccination options for prevention. The problem, however, is that a number of men and women in the Peruvian region and in other developing countries do not have the knowledge to seek out preventive services. Interventions specifically addressing the sociocultural barriers that may have an influence on prevention behaviors is lacking. It is important to understand the role of sociocultural factors on a cancer that is caused by a common STI and with the high burden of disease. Culturally sensitive approaches are needed to account for the influence of sociocultural factors. Second, gender ideologies vary across different ethnicities and more research is needed to understand the degree to which sociocultural influences impact cervical cancer prevention and control practices in other parts of the world that experience gender inequalities. Third, involving men in exploratory, formative research to inform interventions and incorporate their perspectives on health education messages about HPV and cervical cancer is critical and necessary for men in all parts of the world. Fourth, the dissemination of health communication messages about cervical cancer through desired and accessible channels provides an opportunity to embrace behavior change through culturally centered methods of communication.

Preliminary work in Cusco has demonstrated the potential influence of the sociocultural context as an underexplored perspective to understand in conjunction with the known issues of access, infrastructure, and clinical capacity. Given my background in cervical cancer and HPV interventions, qualitative research, and preliminary work done in this region, I am well positioned to provide this dissertation research as a means to address the problem of cervical cancer disparities in the underserved populations of Cusco, Peru.

The research has the potential to advance knowledge and understanding of cancer prevention and control behaviors by incorporating the perspectives of men in understanding how cervical cancer affects men and women and using a sociocultural approach to account for the beliefs, stigma, and gender ideologies associated with the transmission, treatment, and survival of cervical cancer. Exploring differences in perspectives between urban and rural populations may yield additional insight on how to address cervical cancer screening behaviors within specific ethnic subgroups as opposed to generalizing findings to specific ethnic populations.

### **Theoretical background**

The theoretical background for the dissertation research derives from the PEN-3 framework in order to account for the cultural influences on health behaviors and outcomes in areas within low resources to facilitate education around particular health topics (Iwelunmor, Newsome, & Airhihenbuwa, 2014). It is also predicated on the social contagion theory which discusses the mechanism for which information is spread and behaviors are influenced through interpersonal communication.

The PEN-3 model developed by Collins Airhihenbuwa addresses the need for a cultural approach to understanding ways culture is embedded into ideas, practices, and beliefs around a particular health topic (Airhihenbuwa, 1990). The foundation of the PEN-3 cultural model is based on three main domains and three PEN elements within each domain that make up the acronym (Iwelunmor et al., 2014). The model usually starts with the Cultural Identity domain which includes the PEN elements of Person, Extended family, and Neighborhood. These describe the interpersonal relationships between immediate family, distant family, and larger communities within a network of people. The model continues clockwise with the Relationships and Expectations domain and includes the elements of Perceptions, Enableers, and Nurturers. These elements address attitudes or beliefs about a particular health issue, the resources made available (or not) to address that issue, and the role of the family as decision nurturers about managing the health issue. Finally, the Cultural Empowerment domain includes Positive, Existential, and Negative elements. These address beliefs and behaviors about health issues that are positive, those that simply acknowledge existence of a health issue, and those that pose challenges or barriers to health outcomes (Iwelunmor et al., 2014).

The concept of social contagion from the psychology perspective is that “the spread of affect or behavior from one crowd participant to the another where one or more persons serve as the stimulus for the imitative actions of another” (McGuire, Lindzey, & Aronson, 1985). Scherer and colleagues describe social contagion as individuals that adopt ideas and behaviors of others in their networks they consistently communicate with (Scherer & Cho, 2003). It may not be that one entity purposely to influence the other, but

more that the communication about the behavior between two or more parties is enough for adoption (Scherer & Cho, 2003).

Social influence may have a great deal to do with the contagion of negative emotional and idealistic views surrounding cervical cancer screening and preventive options. The examination of the use of opinion leaders in communities that are proponents of these services would provide valuable insight to the surrounding community members screening practices. One study found that women that had higher education and and/or income were among the early adopters of cervical cancer screening than women of lower income, despite the availability of free or reduced screening services (Hahm et al., 2011). Implications for communication strategies could also be informed by social contagion, particularly to reverse negative views of screening and vaccination by influencing both the emotional and behavioral barriers to screening and prevention services.

### **Conceptual model**

Building on the theoretical foundation, the conceptual model for the dissertation research breaks down the application of the PEN-3 constructs as they relate to the three main areas of focus, cultural beliefs, cultural stigma, and the presence or absence of the *marianismo-machismo* gender ideology on cervical cancer prevention and control behaviors. It goes on to illustrate the added role of media channels within a culture with the inclusion of interpersonal communication to facilitate cervical cancer education and ultimately improve screening and prevention behaviors (Figure 2.1).

Cultural identity and how people in a community perceive a disease can have a great deal to do with how it is treated both physically and socially. If the common belief among *persons* such as mothers, healthcare workers, *promotoras* and others is that gynecologic issues and maladies related to a woman's body are not discussed, preventive measures such as cervical cancer screening will not be discussed or treated as a preventive behavior (Ashing-Giwa et al., 2004; Luque, Maupin, et al., 2016). The *extended family* such as grandmothers, aunts, cousins and other female elders in the family could exacerbate ideas related to the absence of prevention which in turn spread and become common practice in *neighborhoods*, villages, and communities. Negative attitudes and misperceptions then become deeply embedded in a family, a society, and a culture. As an example, knowledge has been shown to be a barrier to cervical cancer screening. Women in many Latina populations around the world do not know how cervical cancer is caused or if there are symptoms (Aguilar et al., 2016; Agurto et al., 2004a; D'Orazio et al., 2014; Luque, Maupin, et al., 2016). This lack of knowledge can in turn create avenues for cultural remedies and myths to be circulated in communities due to the lack of educational programs and clinicians bringing up the need for a Pap test when they go to the doctor for other things (Bayer et al., 2011; Luque, Maupin, et al., 2016).

Similar to conversations of sexual matters being misunderstood or even silenced, cultural identity overlaps with relationships and expectations, where the *marianismo-machismo* dynamic might be at play. The cultural *perceptions* and *marianismo* ideologies of purity, modesty, submissiveness, and devotion to one's family do not align with a need for a Pap test because it is associated with a sexually-transmitted infection, thereby

implying promiscuity, dishonor, and disgrace of the home (Daley et al., 2010; D’Orazio et al., 2014; Dyer, 2010; Flores & Bencomo, 2009). Those that perpetuate the *marianismo* ideologies in a community are known as *enablers* and could potentially double as the extended family and neighbors identified in the cultural identity domain. The *nurturers* in the model are people that influence decisions regarding healthcare practices which in this case would be obtaining regular Pap tests. The dynamic between husband and wife and the degree to which the presence of the *marianismo-machismo* dynamic operates in the home, may or may not threaten the need for regular Pap test due to misunderstandings of what happens during screening procedures or what it means if cervical abnormalities are found (Erwin et al., 2010; Fernandez et al., 2009; Luque, Maupin, et al., 2016).

The relationships and expectations domain also overlap with the cultural empowerment domain. Here, there is the potential for the husband to be the primary giver of social support and serve as a *positive* influence that goes to screening and follow-up appointments and supports the health of his partner (D’Orazio et al., 2014). This could also be true of women that regularly get screened, neighbors, family members that attend the mobile campaigns, and those that encourage other women to get screened regularly. Examples of *existential* cultural empowerment might include traditional medicine, natural healers, and the role or the presence of the faith community (Erwin et al., 2010). While these do not have a direct relationship to cervical cancer screening, they do not take away from screening behaviors and are instead an embedded part of Latin American culture. *Negative* factors toward empowerment for screening include *fatalismo* or fatalistic beliefs about cancer, fear of diagnosis and an automatic death sentence, stigma with screening or

diagnosis, shame as cervical cancer is associated with an STI, lack of social support, cultural and religious beliefs and ideals toward cancer (D'Orazio et al., 2014).

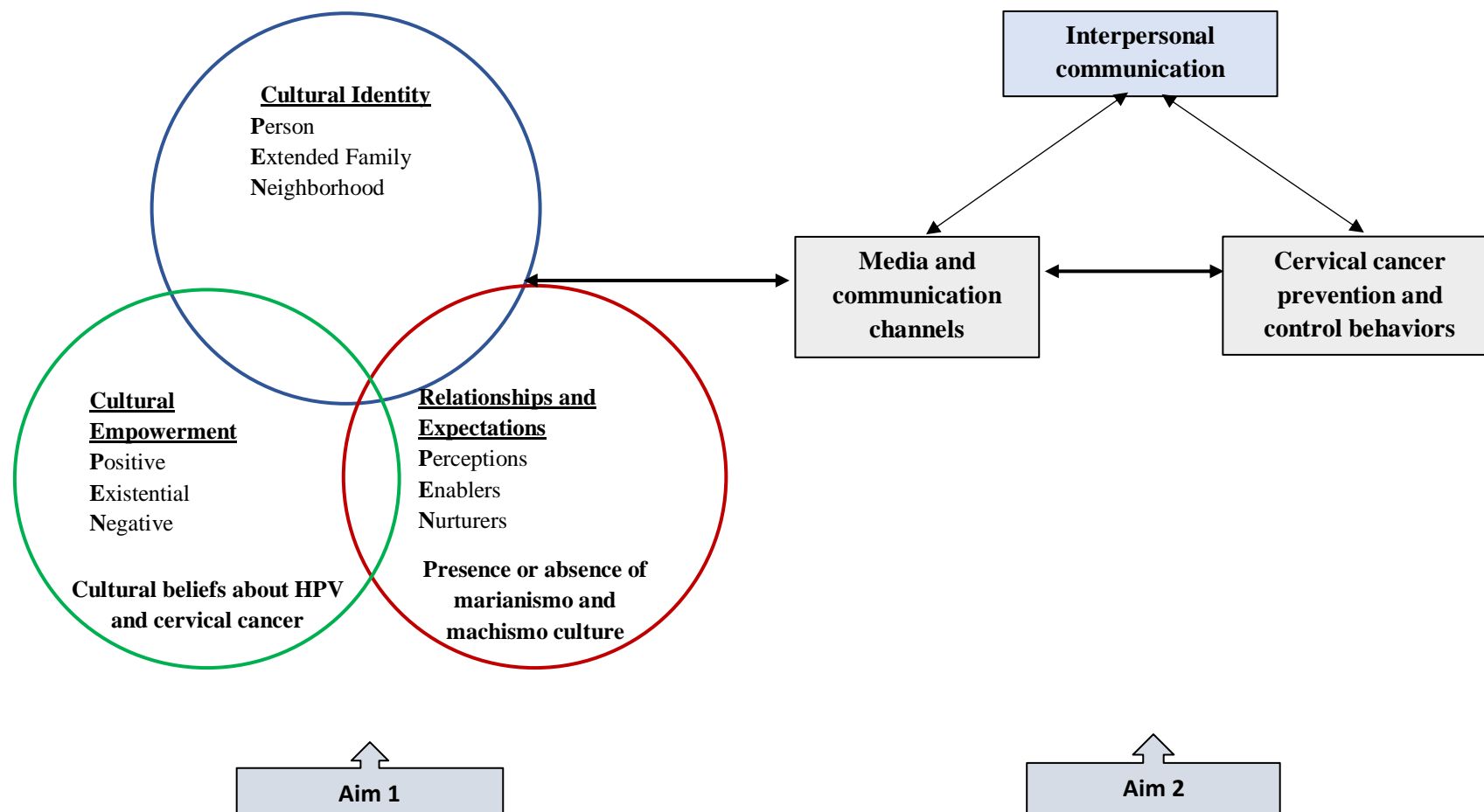
Development of mass media campaigns that are inclusive of culturally-centered and culturally-sensitive approaches have been called for in the literature modestly (Dutta, 2007; E. Torres, Erwin, Trevino, & Jandorf, 2013; Wilkin, Gonzalez, & Tannebaum, 2015). This study informed ways to incorporate culture in health communication channels while advocating for cervical cancer prevention and control behaviors. The conceptual model calls attention to the specific role of interpersonal communication as a mediating pathway to spread information through this mechanism of communication. It is here that the application of Valente's two-step flow hypothesis is operationalized where certain people in the Cusco region would be exposed to the information via a mass media channel and the information would then be transferred either directly to behavior change or through interpersonal communication and personal networks to introduce cervical cancer information and ultimately behavior change (Valente, 2011).

It is important to note the bi-directionality of this model. It can be thought of as the sociocultural constructs situated in the PEN-3 model will have an influence on health communication and ultimately cervical cancer prevention and control behaviors among Peruvian women, but it is also important to recognize the possibility of women who have been screened and how they influence the communication landscape, and ultimately the social culture as it relates to attitudes towards cervical cancer prevention. This concept might be even more important for populations in rural Peru that are likely not exposed to mainstream mass media channels about cervical cancer and rely heavily on information through word of mouth. A breakdown of each of the PEN-3 domains and health

communication approaches and how they were applied in the interview questions for women, men, and clinicians to gather information about each construct can be found in Chapter 3.

The current chapter has detailed the burden of cervical cancer in Peru, and the comparison of cervical cancer screening recommendations and screening practices between Peru and the U.S. Cervical cancer prevention and control measures were described related to the Pap test and VIA screening, HPV vaccination, and the differences in recommendations and screening practices between Peru and the U.S. The chapter also covered a discussion of the literature on what has been done to address the cervical cancer burden in Peru as well as the identified barriers to screening that have contributed to the disparities of cervical cancer throughout the region., The discussion subsequently moved toward the use of health communication channels and interpersonal communication for potential interventions to improve cervical cancer knowledge in both urban and rural communities, given the differences in availability of resources. Gaps in the literature were synthesized to focus on what the dissertation research aimed to cover and concluded with a discussion on the theoretical foundation of the dissertation work and the conceptual model that informed data collection and analysis.





**Figure 2.1.** Conceptual framework (adapted from Airenhenbuwa 1999)

## CHAPTER 3

### METHODS

#### **Introduction and Overview**

The goal of the dissertation research was to identify sociocultural influences that impact cervical cancer prevention and control behaviors among men and women in Cusco, Peru. More specifically, this study examined sociocultural beliefs about HPV, the Pap test, and cervical cancer, gender ideologies, stigma, and preferences for health communicating channels for cervical cancer and screening practices framed by two Specific Aims:

Aim 1: To explore the influences of cultural beliefs, stigma, and *marianismo-machismo* gender ideologies on cervical cancer prevention and control behaviors among men and women in urban and rural areas of Cusco, Peru. More specifically, three primary topics were explored in detail: 1) cultural beliefs and practices that may exist among women related to cervical cancer, 2) the role of stigma related to HPV and cervical cancer and its impact on cervical cancer screening behaviors, and 3) assessing the presence of the *marianismo-machismo* gender ideology and its impact on cervical cancer screening behaviors of women in urban and rural areas of Cusco, Peru. Understanding the role of these sociocultural influences on cervical cancer prevention and control behaviors can provide key insight to inform the development of culturally-tailored interventions and health communication for Cuscainian men and women.

Aim 2: To identify preferences for health communication channels to increase cervical cancer prevention and control behaviors among men and women in urban and rural areas of Cusco, Peru. The second aim of this study also used a qualitative approach to understand the preferred channel(s) for cervical cancer education materials that are conducive to their culture and available resources. Similarly, information was gathered on the role of interpersonal communication as a channel for health information. Specific questions were asked to identify preferred channels and strategies for cervical cancer information, and in the case of interpersonal communication, methods for which they would like to receive information.

The subsequent sections of this chapter will discuss the approach to the study and why a qualitative approach was warranted. It will review the study setting, where participant recruitment took place, and the instruments that were developed for data collection. The chapter will further detail the process of data collection, how the data were managed and cleaned for analysis, and the processes for analyzing and synthesizing the data.

## **Research Design**

The level of information that can be obtained by using qualitative methods can generate data that is more far reaching than what quantitative approaches alone can achieve. Given the topic of social and cultural behaviors and its influence on cervical cancer screening, a qualitative method lends itself to discussion that provides context, insight, and the lived experiences as they relate to cultural beliefs, stigma, and gender roles in cervical cancer screening and prevention. In the case of aim two, using a

qualitative approach to gather health communication data yields itself to contextual information as to reasons why people prefer the communication channels they do, and who they are willing to learn health information from.

Compared to other qualitative traditions of inquiry including grounded theory, case study, and narrative research; the phenomenological and ethnographic approach were deemed the most appropriate methods because of its purpose to understand the lived experiences of people as it related to cervical cancer prevention and control behaviors. The fieldwork associated with the collection of phenomenological data lends itself to ethnographic approaches particularly if one is to produce a narrative that is inclusive of the participant's (emic) and researcher's (etic) interpretations (Bloomberg & Volpe, 2016). Ethnographic studies can also increase the quality of the phenomenological interpretation by having the appropriate context of the culture being sampled (Bloomberg & Volpe, 2016; Flowers, Larkin, & Smith, 2009). The phenomenological method takes on an interpretive approach to the topic which is needed given discussions having to do with sex, sexual transmission of diseases, myths, beliefs, and cultural implications on health care (Bloomberg & Volpe, 2016). It also requires a summation of individual experiences in order to illuminate the central characteristics of the phenomenon itself (Bloomberg & Volpe, 2016; Breakwell, 2004). One limitation to the use of a phenomenological approach is that it has the potential to introduce issues of quality and methodologic rigor. In addition to the use of an ethnographic method to reduce bias in interpretation, efforts to increase quality, validity and reliability have been taken and will be discussed in greater detail later in this chapter.

## Setting

As of 2017 the total population in the Andean region of Cusco Peru was just over 1.2 million (“Peru: Cusco Region (Provinces and Districts) - Population Statistics, Charts and Map,” n.d.) (Figure 3.1). In 2015, Peru was considered an upper-middle-income country, yet poverty rates in rural areas were approximately three times higher than in urban areas (“PERÚ Instituto Nacional de Estadística e Informática,” n.d.). Concerning the areas visited in this study, the total population size in the rural towns of Ollantaytambo, Chinchero, Urcos and Yaurisque collectively was 33,180. The population size in the urban district of San Jerónimo was 57,065 (“Peru: Cusco Region (Provinces and Districts) - Population Statistics, Charts and Map,” n.d.). The setting for the research study took place across various districts of Cusco, Peru. Within the San Sebastian district of Cusco is a clinic that specializes in women’s health called CerviCusco. Established in 2008, CerviCusco has provided Pap tests to approximately 10,000 women each year and is the only clinic that provides liquid-based cytology in the Andes region of Peru (“Cervi Cusco,” n.d.; Luque, Maupin, et al., 2016). The CerviCusco stationary clinic has normal clinic hours from 8am to 2pm, Monday through Saturday. Mobile campaigns are mobile clinics that are organized in partnership with government agencies of rural districts, area clinics, and community members to offer screening and vaccination services to women and children that are not able to access care due to the distance needed to travel to stationary clinics. Four to five mobile campaigns are



**Figure 3.1 Map of South America**

scheduled each week beginning at 6am with the heaviest campaign schedule occurring between May and August. partnership was created with the clinic during the summer of 2017 that would allow for the recruitment of participants for this study in the summer of 2018.

### **Sampling and Recruitment**

Three sampling strategies were used to execute the project. Overall, the study used a purposeful sample technique with Cusco as the chosen city within Peru, and women, men, clinicians as the subjects within the city. From here, stratified purposeful sampling was used to break the sample into subgroups for comparison. For the data

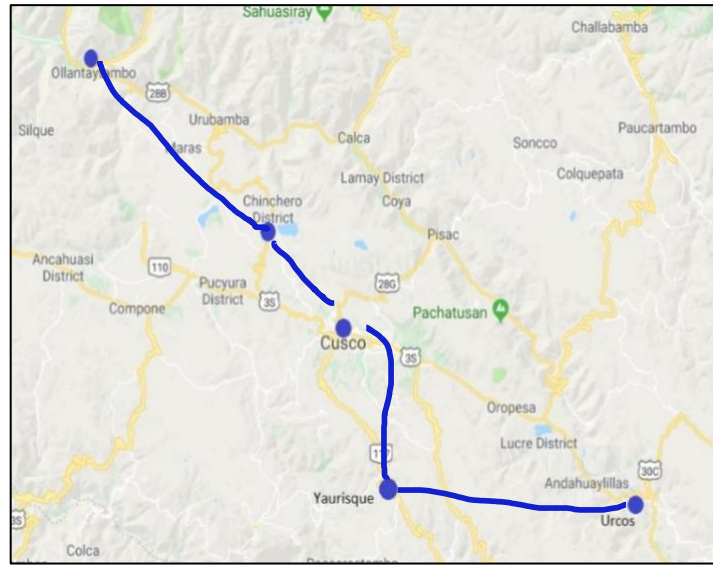
gathered, all of the women, men, and clinicians in the sample were selected for participation and stratified by urban and rural locations. The urban rural comparisons were important to distinguish due to variations in health care access, quality, and mindset of prevention. Provided that this study implemented a phenomenological approach, it was especially important to implement a criterion-based sampling strategy which meant that all women, men, and clinicians had to meet the inclusion criteria set for the study. Having this type of criterion allowed for the research questions to be explored across a group of participants that had the same characteristics so that the phenomenon could be explored in depth. A time-space or purposeful random sampling technique was also implemented because participants that met the inclusion criteria were recruited and selected at random times, days of the week, and locations. For example, women and men that were approached in clinics were selected at random and then determined if the inclusion requirements were met if they indicated a willingness to participate. Likewise, all participants recruited outside of clinics were approached and recruited based on their eligibility and willingness to participate in the interview. Sampling outside of the clinic was done in effort to reduce the potential bias of those already seeking health services related to cervical cancer. In all cases, there was not a standard location, time or day of the week that sampling, or recruitment took place making the approach randomized within the purposeful sample (Bloomberg & Volpe, 2016).

Recruitment of study participants took place in both urban and rural areas of districts of Cusco. Female participants in urban areas were invited to participate in the study upon the completion of their Pap test at the CerviCusco clinic and males accompanying their partner or family member to the clinic were also recruited during

their appointment time. Female participants not associated with the CerviCusco clinic were recruited to participate in area markets and other community settings. Similarly, female participants in rural areas were asked to participate in the study at the completion of their Pap test during one mobile clinic organized by CerviCusco. Recruitment in all other rural sites was sought out by the researcher. Rural areas outside of the CerviCusco clinic for female and male participants included Ollaytantambo, Chinchero, Yaurisque, and Urcos. Urban areas for recruitment and interviews outside of the CerviCusco took place in the Plaza de Armas, and Qorichancha. Clinician participants were recruited in both urban and rural areas as they were interested and had the time to participate (Figure 3.2).

The inclusion criteria for the study were women age 25 - 60, have never received a Pap test, had not adhered to recommended Peruvian screening recommendations, and those who were up-to-date with screening. Men who had partners and/or family members eligible for a Pap tests were also recruited to participate. Clinicians who provide cervical cancer prevention and control services such as vaccinations or Pap tests in urban or rural clinics were also eligible to participate. Clinicians were included in the sample to gather their perspectives on the impact of sociocultural influences on cervical cancer screening practices among their patient populations and any ideas they may have about health communication interventions that would be suitable for their patients. Further, they are residents of the community and hold important insights into social and cultural influences. As such, clinician interviews were used to triangulate the data from the male and female interviews (Bekhet & Zauszniewski, 2012; Miles, Huberman, & Saldaña, 2014). The exclusion criteria for the sample included women who had a hysterectomy,





**Figure 3.2** Map of Recruitment Sites in Cusco

did not meet the age recommendation to have a Pap test, or men and women who were not willing to participate in the interview alone (i.e. a male partner that requires to be present during the interview with a female participant).

Five urban female participants were approached to participate at the CerviCusco clinic. Urban women outside of the clinic were approached about the topic through word of mouth and other participants recommendations and were scheduled to come to the clinic to participate in the interview (n=2). The response rate for urban female participation was 6/9 (66%). Rural female participants were recruited during one CerviCusco mobile campaign in Ollantaytambo (n=4) after the completion of their Pap test. Other rural females were recruited in municipals of Chinchero (n=3), and a general clinic in Yaurisque (n=5). The response rate for rural female participation was 12/15 (80%). Urban male participants were approached in the Plaza de Armas and other local

areas and interviews were often conducted on benches or nearby quiet shops. Clinicians were approached about the study in urban and rural clinics and appointment times were scheduled as they indicated interest. The criterion for sample size was determined by saturation, that is, until no new information was gathered from succeeding interviews from the eligible populations (Bernard, 2017, p. 200; Guest, Bunce, & Johnson, 2006).

### **Instrumentation and measurement**

Three interview guides were used in this study and were developed based on questions related to cultural beliefs situated within each of the PEN-3 domains, social network characteristics and health communication preferences with support from existing literature (Castillo et al., 2010; Luque, Opoku, Ferris, & Guevara Condorhuaman, 2016; Ragan, Lunsford, Smith, Saraiya, & Aketch, 2017).

The interview guides for women began with general demographic questions such as age, primary language spoken, if they consider themselves and urban or rural resident, highest education achieved, marital status, and if they had ever received a Pap test before. If women indicated that they had received a Pap test, a follow up question was asked about the last time they had one. For women that were interviewed in a clinic setting, they were additionally asked if they were there for prevention, or if they were experiencing any symptoms. The remaining questions in the guide were divided into four sections:

- 1) Knowledge about HPV, the Pap test, and cervical cancer:** The first section included individual open-ended questions about what they knew about HPV, a Pap test, and what they think causes cervical cancer. Following this conversation,

an informational paragraph about each of these topics was read to the participant.

The excerpt was written and adapted from the Centers for Disease Control and Prevention cervical cancer page (“Basic Information about HPV and Cancer | CDC,” 2019).

**2) Sociocultural influences:** The second portion of the guide asked specific questions and probes related to sociocultural influences such as experiencing shame or embarrassment getting a Pap test, willingness to talk to others about the Pap test and cervical cancer, support from a spouse or partner to get screened, fear of the exam or anyone that made them afraid to get a Pap test, and what they have heard members in their community say about getting a Pap test or about cervical cancer.

**3) Health communication channels:** The final section of the interview guide asked women how they would like to receive information about HPV and cervical cancer, in addition to other things that they would be interested in to remember information about HPV and cervical cancer.

The guide for men was modeled similarly to the guides for women. Men were also asked general demographic questions at the beginning of the interview. In addition to their knowledge about HPV, the Pap test, and what they think causes cervical cancer. The same educational information was read to each of the male participants after they answered the knowledge questions. The same knowledge questions were asked of the male participants prior to the educational segment that was provided about general HPV and cervical cancer information. Male participants were asked similar questions related to sociocultural influences as females with some variation. Men specifically were asked,

who in their community might be against getting a Pap test, what are any reasons a man might not want their spouse or partner to get a Pap test, are there any community groups that they know of that oppose cervical cancer screening, and if they have or have not had conversations with their spouse, or female family members about getting a Pap test and why or why not. This line of questioning was developed in part because in Latin America and Peru, healthcare decisions are ultimately decided by the male head of household (Nuñez et al., 2016).

In keeping with the structure of the guides for women and men, clinicians were asked about the general demographics of the patients they serve, the number of patients they see on a weekly basis, and the average age of women when they get their first Pap test. Information about the clinicians' gender, role in the clinic, and length of time at the clinic were also asked. Similar to the guides for women and men, the guide was developed into four parts. Clinicians were asked to speak about what they have heard their patients disclose about HPV, the Pap test, and cervical cancer knowledge. They were also asked about any experiences their patients share with them about previous Pap tests. Similar to the guide for women, clinicians were asked about instances where their patients were ashamed or embarrassed to get a Pap test, the interactions between the men and women that come to the clinic and the level of support that is given or received, and conversations if any, women and men have about the Pap test and cervical cancer. Similarly, clinicians were asked their opinions about what types and channels of health communication they thought would be beneficial for women and men in the communities to receive related to the Pap test and cervical cancer. As mentioned in chapter 2, Table

**Table 3.1 Application of PEN-3 constructs in data collection**

<b>PEN-3 Domain</b>	<b>Conceptual Model Constructs</b>	<b>Interview Guide (Women)</b>	<b>Interview Guide (Men)</b>	<b>Interview Guide (Clinicians)</b>
<b>Relationships and expectations</b> Perceptions Enablers Nurturers	<b>Marianismo</b> <b>Machismo</b>	<i>If you are married or have a significant other, how supportive are they of you getting preventative health services such as a Pap test?</i>	<i>What are some reasons a man might not want his wife/partner/female family member to get a Pap test?</i>  <i>Who in your community might be against women getting a Pap test?</i>	<i>What roles have you seen husbands/partners/male family members play in women getting Pap tests?</i>
<b>Cultural empowerment</b> Positive Existential Negative	<b>Cultural beliefs</b>	<i>What have you heard other members in your community say about getting a Pap test or about cervical cancer?</i>	<i>What have you heard members in your community say about getting a Pap test or about cervical cancer?</i>	<i>What myths have you heard related to cervical cancer and Pap test?</i>
<b>Cultural identity</b> Person Extended family Neighborhood	<b>Stigma</b>	<i>Please tell me about any times you may have experienced feelings of embarrassment or shame getting a Papanicolaou test?</i>	<i>If you have not had any conversations with the women in your life about a Pap test or cervical cancer, tell me about some of the reasons that have kept you from talking about it.</i>	<i>Please tell me about any experiences you may have had with your patients feeling ashamed or embarrassed getting a Papanicolaou test?</i>

3.1 provides a breakdown of each PEN-3 domain and an example interview question for female, male, and clinician participants applicable to each construct.

The interpreter on the research team was trained on the original interview guide prior to the start of data collection. Following the training, the guide was piloted with a male community participant to assess timing, translation, and logistics. Two female interviews were also piloted in the clinic setting. Another member of the research team who is a native speaker of Peru also provided feedback on the guide. The changes from the pilot interviews and research team input were discussed. Changes to the guide included the omission of questions that were either redundant, not relevant, poorly worded, or were not comprehended by participants. Other minor changes to guides were made after the first five male and first three female interviews. These changes included order and rephrasing of questions, and the addition of probes where needed. The final version of the interview guides can be found in Appendix A.

### **Data collection**

Semi-structured interviews were conducted with 20 females, 13 males, and six clinicians across urban and rural locations of Cusco, Peru until saturation was reached and no new information was gathered from participants (Creswell, 1998; Strauss & Corbin, 1990). Interviews were conducted in Spanish or Quechua with a member of the research team fluent in both languages and trained on the study protocol. Prior to the start of the interview, the consent form was reviewed with each participant. Participants were informed that the interview would be audio recorded and that their names were not going to be used in the written transcript. Each female interview lasted approximately 45

minutes, male interviews, 30-35 minutes, and clinician interviews, 40 minutes. A field note template was used to record observations pertaining to each interview environment, analytic and methodological observations, and overall quality of the interview.

Completed field notes accompanied each transcript and were referenced during data analysis and interpretation as necessary. Field notes that accompanied each interview were designed to capture body language, non-verbal cues, surroundings and external influences as it impacted the interview setting. Each participant received S./20 PEN (Peruvian soles) or \$7 USD (currency conversion at the time of the study) for their time. Prior to any data collection activities, an IRB application was submitted and approved by both the University of South Carolina and Peruvian Institutional Review Boards.

### **Data management**

Data were de-identified, transcribed in Spanish, then translated into English. In instances where the participant only spoke Quechua, audio files and transcripts were verified by a native Quechua speaker and then translated into English. Each interview was assigned a unique participant ID number and was transcribed by two members of the research team who spoke Andean Spanish. Spanish and English transcripts were cross checked between members, comparing the transcript to the audio recording for accuracy. All interviews transcripts, field notes, and other data points were up loaded into Dropbox serving as the projects' repository.

### **Validity and reliability of transcriptions and translations**

First draft transcriptions were divided between two members of the research team. Each member transcribed either male, female, or clinician audio files verbatim in Spanish

and sent the first draft transcript to the other member to verify the transcription. Any discrepancies between the team members were reconciled before moving to the next step. Following the verification of Spanish transcriptions, the same two team members translated each male, female, and clinician Spanish transcription into English and swapped again with the other team member to verify the English translation. In the case of the Quechua interviews, one research team member transcribed the interview in Quechua and verified the transcription with a native Quechua speaker while in country. Once the written transcript was reviewed against the audio file, the interview was then translated into English. Once the second English translation was verified, the transcript was cleaned and finalized for analysis. Special care was taken to implement a transcription and translation validity procedure since the interviews were conducted with Andean Spanish or Quechua participants. Members of the research team included a native Andean Spanish speaker of Peru, and a linguist that specialized in romance Andean languages including Spanish and Quechua.

### **Data Analysis and Synthesis**

The initial codebook was developed by hand based on provisional coding from the interview guide. The next iteration of the codebook was from hand coding the first two female and male interview guides. To minimize bias of personal interpretation of the initial coding scheme, four female (two urban and two rural), four male (two urban and two rural), and one clinician transcript was coded followed by an independent review of the same transcripts by a second reviewer. Differences in coding were resolved between the coders and the remaining transcripts were coded based on this coding schema during



the first cycle coding process. This set of transcripts was reviewed against the first draft of the codebook developed from the interview guide then modified accordingly. Once the coding schema was determined, the codes were entered into NVivo® 11 Plus (QSR, 2010). Subsequently a codebook was generated in NVivo from the codes entered and underwent a total of four revisions based on emergent codes and card sort discussions.

In line with a qualitative phenomenological approach, an interpretive phenomenological analysis was used to synthesize the themes that emerged from the data. Interpretive phenomenological analysis is approaching the data to explore and understand the experiences of individuals in this case as it relates to cervical cancer, directly from the participants perspective (Breakwell, 2004). The major themes that emerge from the collective group of participants with examples directly from the participants words that illustrate each theme. This gives the participants a “voice” in the narrative depiction of the phenomenon under study. During the first cycle coding process, themes were derived from a combination of provisional, hypothesis, emergent, and the values, attitudes, and beliefs coding methods (Miles et al., 2014). Initial themes were then recoded and interpreted using the pattern and axial coding method during the second cycle coding process. The next step was to verify the themes that emerged with a second coder through the card sort method (LeCompte, 2000; Waite, 2011) to eliminate single coder bias. The two coders discussed similarities and differences in the individual sorts to determine the final most salient themes from the data. A second cart sort was then done to apply each of the themes to the PEN-3 portion of the conceptual framework. Again, two coders independently placed the themes where they believe they fell within the PEN-3 framework based on the quotes within each theme, and the definition of each PEN-3

construct. The next step was to matrix code the themes based on PEN-3 constructs to look for interactions within the cultural experience as it relates to cervical cancer screening behaviors. The two coders met to discuss the similarities and differences between their individual card sorts until reaching a consensus on the application of all of the themes to the intersections of the framework.

NVivo® 11 Plus software was used for all data organization and analysis. NVivo® 11 Plus was also used to analyze all social network data from the interviews. Social network data were coded by participant as the ego, the relationship type as the tie (family, friend, neighbor, coworker, etc.) and the named person(s) as the alter(s). Other characteristics of the participants network were coded to each participant (ego) based on the information they provide in the interview. Sociograms were then generated for each participant and the qualitative information gathered from the interview about each alter was used to explain the context of the participants' network and the influence each alter had on that persons' views about the Pap test.

## **Chapter Summary**

This chapter described the process of how the dissertation research was executed. Before presenting the findings that emerged from this process, this chapter connected the process for sampling and recruiting a final sample of 39 participants and the process for which data were collected. Details about the management of the data were discussed and linked to the preparation for the multistep data analysis process. Each manuscript included methods specific to the purpose of the specific aim that it addressed. Table 3.1 provides a summary of the subsequent manuscripts related to each specific aim.

**Table 3.2 Summary of manuscripts by specific aim and research question**

<b>Manuscript title</b>	<b>Specific aim</b>	<b>Research question</b>
Sociocultural influences on cervical cancer screening uptake in Cusco, Peru: A qualitative study	Specific Aim 1	What cultural beliefs impact cervical cancer screening among women, men and clinicians in Cusco, Peru?
The impacts of gender dynamics on cervical cancer screening practices in Cusco, Peru	Specific Aim 1	How do gender dynamics impact cervical cancer screening behaviors in urban and rural communities in Cusco, Peru?
Preference for health communication channels to increase cervical cancer knowledge and screening in Cusco, Peru	Specific Aim 2	What are the preferred channels for communicating health information about cervical cancer among women and men in Cusco, Peru?

## CHAPTER 4

### RESULTS

Results from the dissertation work are divided into three subsequent manuscripts and prepared for submission to two peer reviewed journals. The first manuscript details the findings related the first aim of the study regarding the sociocultural influences on cervical cancer prevention and control behaviors among women and men in Cusco, Peru. The second manuscript focuses on the gender dynamics on cervical cancer screening practices in Cusco, Peru and is also associated with aim one of this study. The third and final manuscript discusses findings from aim two that focused on the health communication preferences of participants in Cusco, Peru, and the channels they preferred to receive health information about HPV and cervical cancer.

MANUSCRIPT 1

SOCIOCULTURAL INFLUENCES ON CERVICAL CANCER  
SCREENING UPTAKE IN CUSCO, PERU: A QUALITATIVE STUDY<sup>1</sup>

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<sup>1</sup> Haynes, V.E., Brandt, H.M., Friedman, D.B., Bateman, B.D., Simmons, D., Ferris, D.G.  
To be submitted to *Healthcare for Women International*

## **ABSTRACT**

The goal of this study was to explore cultural beliefs impacting cervical cancer screening uptake in Cusco, Peru. Semi-structured interviews were conducted with 40 women, men and clinicians across urban and rural communities. Six themes were extracted from the data including the purpose of the Pap test, causes of cervical cancer, related fears, embarrassment evoked by Pap tests, community conversations about Pap tests and cervical cancer, and willingness to talk about cervical cancer. Findings suggest sociocultural influences impact cervical cancer screening behaviors and there is an overwhelming need for interventions addressing these influences among women and men in Cusco, Peru.

Key words:

Cervical cancer, screening, Pap test, culture, Peru

## INTRODUCTION

Cervical cancer is one of the most preventable cancers, however it continues to be a significant health challenge for women in low and middle-income countries (LMICs), particularly in Latin American countries (Aguilar et al., 2016). Compared to the rest of the world, cervical cancer incidence and mortality is excessively high in Peru, where the cervical cancer incidence rate is 23.2 cases per 100,000. This is almost four times higher than in the United States (U.S.) where incidence rates are 6.5 cases per 100,000 and nearly double the worldwide incidence rate of 13.1 cases per 100,000 (Bray et al., 2018). The cervical cancer mortality rate in Peru is 10.2 deaths per 100,000. This mortality rate is nearly five times higher than in the U.S. at 1.9 deaths per 100,000 and nearly doubles the worldwide mortality rate of 6.9 deaths per 100,000 (Bray et al., 2018). Cervical cancer poses a significant burden among Peruvian women.

Previous studies conducted in Latin America (i.e. Venezuela, Ecuador, Mexico, El Salvador and Peru) have examined issues of access, availability, and geographical determinants of cervical cancer incidence and mortality. They conclude that differences in cancer outcomes are related to access to cervical cancer screening and treatment services (Agurto, Bishop, Sánchez, Betancourt, & Robles, 2004; Almonte et al., 2011; Bychkovsky et al., 2016; Luque, Maupin, Ferris, & Condorhuaman, 2016). Additionally, studies on cervical cancer prevention in Colombia and Northern Peru attribute the lack of prioritization for and absence of screening behaviors to societal beliefs or misconceptions about the disease (Wiesner, Cendales, Murillo, Piñeros, & Tovar, 2010; Wiesner-Ceballos, Vejarano-Velandia, Caicedo-Mera, Tovar-Murillo, & Cendales-Duarte, 2006; Winkler, Bingham, Coffey, & Handwerker, 2008). Those most commonly mentioned

include “improper” hygiene, having one or too many abortions, genetic susceptibility, promiscuity, and the use of birth control (Granda-Cameron, 1999; Paz-Soldán, Nussbaum, Bayer, & Cabrera, 2010). Some women presume a Pap test is administered to cure a fungus or bacterial infection, clean the vaginal area, or diagnose a uterine cancer. They also suspect it will be a painful or traumatic experience (Paz-Soldán et al., 2010; Wiesner-Ceballos et al., 2006). Consequently, the opportunities for misinformation about the Pap test evolve into commonly held beliefs that are widely diffused across and within societies and cultures (Paz-Soldán et al., 2010).

Barriers to cervical cancer screening among South American women, including urban areas of Peru, are related to mistrust with the healthcare system, lack of spousal support, and embarrassment exposing genitals to a male physician (Agurto et al., 2004; Luque et al., 2016; Paz-Soldán et al., 2010). Other study findings have included the cultural preferences and practices of traditional medicine, indigenous healers (*curanderos*) and using home remedies to self-treat at the presence of cancer symptoms (Granda-Cameron, 1999; Luque et al., 2016; Paz Soldan et al., 2008). Studies in these populations also cite familial priorities (i.e. child-rearing, work, home-related obligations) as reasons women do not receive cervical cancer screening (Agurto et al., 2004; Luque et al., 2016; Paz Soldan et al., 2008; Paz-Soldán et al., 2010; Wiesner-Ceballos et al., 2006). Health-related stigma also exists in South America, which some consider a cultural barrier to cervical cancer screening (Gregg, 2011). Weiss et al. (2006) suggest that different cultures assign meaning to certain diseases, and in some cases actually having symptoms of a disease is not as detrimental as being associated with having the disease itself (Weiss, Ramakrishna, & Somma, 2006). Weiss and Yang (2014)



also emphasize the need to understand how stigma manifests itself in different cultures, whether it is self-perceived or enacted stigma (Daley et al., 2010; Dyer, 2010), or through delayed or avoidance of treatment and prevention (Oaten, Stevenson, & Case, 2011; Weiss et al., 2006; Yang, Thornicroft, Alvarado, Vega, & Link, 2014). Issues of access and screening barriers can be improved, structurally and with increased general knowledge about cervical cancer, but screening uptake may remain the same if issues of trust, fear, stigma and cultural misunderstandings are not addressed.

### *Theoretical background*

Defined broadly, culture is a set of ideals mutually agreed upon and adopted by a group of people, which are shaped from similar world views and social norms including, but not limited to, environment, economy, technology, religion, language, social structure, beliefs and values (D'Orazio, Taylor-Ford, & Meyerowitz, 2014; Kagawa Singer, Dressler, & George, 2016; Kagawa-Singer, Valdez Dadia, Yu, & Surbone, 2010). Individual perspectives on health issues vary based on individuals' world views and may determine their course of action to seek treatment or participate in prevention practices (Cadet, Burke, Stewart, Howard, & Schonberg, 2017). The theoretical background for this work was derived from the PEN-3 Model developed by Collins Airhihenbuwa, which addresses the need for a culturally informed approach to understanding ways in which culture is embedded into ideas, practices and beliefs around a particular health topic (Airhihenbuwa, 1990). Building on the theoretical foundation of the PEN-3 Model, this study applied PEN-3 domains of *cultural identity*, *cultural empowerment*, and *relationships and expectations* as they relate to cultural beliefs associated with cervical cancer prevention and control behaviors. Within each domain are three constructs that

make up the PEN acronym. Cultural Identity includes the person, extended family, or neighbourhood constructs within a community that perceives a disease a certain way and influences how it is treated physically and socially. The Cultural Empowerment domain is where cultural influences on cervical cancer screening are determined by identifying beliefs and practices that are positive, those that are existential or do not have harmful health consequences, and those that are negative and serve as barriers. Perceptions and attitudes about a disease are explored in the Relationships and Expectations domain which include the perceptions, enableers, and nurturers that promote or discourage health practices (i.e. Pap test screening). This third domain considers the influence of family and close friends in decision-making related to the uptake of Pap test screening (Iwelunmor, Newsome, & Airhihenbuwa, 2014).

Although studies have looked at structural, systematic and psychosocial barriers to cervical cancer screening, there is minimal research looking at the similarities and differences across Latina populations in South America, particularly as they relate to the role of culture on screening uptake. The goal of this study was to explore cultural beliefs that impact cervical cancer screening among women, men and clinicians in Cusco, Peru. It also aims to illuminate their cervical cancer screening-related experiences and any prevailing cultural beliefs and practices that help or impede screening behaviors. Such information is critical to address the excessive burden of cervical cancer in Peru and the development of interventions for this population.

## **METHODS**

### *Setting*

As of 2017 the total population in the Andean region of Cusco Peru was just over 1.2 million (“Peru: Cusco Region (Provinces and Districts) - Population Statistics, Charts and Map,” n.d.). In 2015 Peru was considered an upper-middle-income country, yet poverty rates in rural areas were approximately three times higher than in urban areas (“PERU Instituto Nacional de Estadística e Informática,” n.d.). Concerning the areas visited in this study, the total population size in the rural towns of Ollantaytambo, Chinchero, Urcos and Yaurisque collectively was 33,180. The population size in the urban district of San Jerónimo was 57,065 (“Peru: Cusco Region (Provinces and Districts) - Population Statistics, Charts and Map,” n.d.).

### *Sample*

Recruitment of study participants took place in Cusco during the summer of 2018. Stratified purposeful sampling was used to recruit females, males and clinicians from urban and rural districts for comparison. These comparisons distinguish variations in health care access, quality and knowledge about cervical cancer prevention and detection. The inclusion criteria for this study included women aged 25-60 years and had never received a Pap test or had not received a Pap test in the previous three to five years. Women who were current with the recommended screening schedule and within the 25-60 age range were also eligible. Men with partners or family members who were of eligible age to receive a Pap test were qualified to participate as were clinicians who provided cervical cancer prevention and control services (i.e. vaccinations and Pap tests) in urban or rural settings. The exclusion criteria for the sample precluded women who

had a hysterectomy, did not meet the recommended age (25-60 years) to receive a Pap test, or whose male partner required to be present during the interview.

Female participants in urban settings were invited to participate in the study upon completion of their Pap tests at a local clinic. Similarly, in rural settings female participants were asked to participate upon completion of their Pap tests during one mobile clinic; recruitment at all other rural sites was sought out by the researcher. Female participants not seeking services through a clinic were recruited in local markets and various settings in the community. Male participants were recruited if they were accompanying their female partners or family members at a Pap test appointment, either at the clinic or during the rural mobile clinic. Male participants not with a woman seeking services were recruited at local taxi stops, area markets and other non-clinical sites. Clinicians were recruited in urban and rural clinics according to their interest and spare time. The criterion for sample size was determined by saturation, that is, until no new information was gathered from succeeding interviews from the eligible populations (Creswell, 1998; Strauss & Corbin, 1990).

### *Instrumentation*

Three interview guides were used in this study based on questions related to cultural beliefs, community relationships, and stigma, and situated within each of the PEN-3 domains with support from existing literature. The interview guide for female participants asked questions related to their knowledge of cervical cancer, Pap tests, HPV and causes of cervical cancer. The female guide also asked about receiving Pap tests, personal experiences with screening, related shame or embarrassment, and what they have heard community members say about the Pap test and cervical cancer. Similarly, the

men's interview guide inquired about their knowledge of HPV, Pap tests and cervical cancer and what they have heard in their community related to these topics. The clinicians' interview guide included some of the topics from the men's and women's guides while gathering clinician perceptions about the Pap test and cervical cancer in the communities they serve. The line of questioning with women, men and clinicians about knowledge of HPV, the Pap test and cervical cancer as well as what they have heard members in their communities say was the means by which cultural beliefs around Cusco were gathered. All three interview guides were pilot-tested with women and men who met the inclusion criteria for the sample.

#### *Data collection*

Data were collected through one-on-one, semi-structured interviews with women, men and clinicians until saturation was reached. Interviews were conducted in Spanish or Quechua, depending on the participants' preferences, by a research team member (BB) who is fluent in Spanish and has extensive experience learning and teaching Quechua. Before data collection began, BB was trained on the study protocol with the lead researcher (VH). Informed consent was obtained from each participant prior to the start of each interview. The duration of the interviews lasted approximately 45 minutes for females, 30 minutes for males, and 40 minutes for clinicians. Each participant received 20 Peruvian soles (S/. 20 PEN), which equalled \$7 USD (exchange rate at the time of the study) for their time. Prior to any data collection activities, an IRB application was reviewed and approved by the University of South Carolina and the PRISMA, Peruvian Institutional Review Board.

### *Data Analysis and Synthesis*

All data were audio-recorded, de-identified, transcribed (in Quechua or Spanish), and translated into English. In instances where the participant was solely a Quechua speaker, audio files and transcripts were verified by a native Quechua speaker prior to English translation. Each interview was assigned a unique participant ID number and was transcribed by two research team members who spoke Andean Spanish. Transcripts and English translations were cross checked between team members, and all transcripts were compared to audio recordings for accuracy.

To minimize bias of personal interpretation of the initial coding scheme, transcripts from four female participants (two urban and two rural) and one clinician were coded by one member of the research team (VH), followed by an independent review of the same transcripts by a second reviewer (WT). Differences in coding were resolved between the two coders through discussion until a consensus was reached. The remaining transcripts were coded based on the determined coding schema during the first cycle coding process. The initial coding structure was derived from a combination of emergent, emotion, and the values, attitudes, and beliefs coding methods during the first cycle coding (Miles, Huberman, & Saldaña, 2014).

The card sort method (LeCompte, 2000; Waite, 2011) was used to collapse coded material into overarching themes and confirm these themes before the second cycle coding process. The initial card sort was independently performed by the lead researcher and given to a second team member (HB) to also independently sort for confirmation. Observed similarities and differences were discussed before moving on to the second cycle coding process. An interpretive phenomenological analysis (Smith & Osborn,

2015) was used to synthesize themes that emerged from the first cycle coding and confirmatory card sort processes. Initial themes were recoded and interpreted into more salient themes using the pattern and axial coding methods. NVivo® 11 Plus software was used for all data organization and facilitated data analysis and interpretation (QSR, 2010). The final step was to card sort the final themes to the cultural domains from the PEN-3 conceptual model as well as any interactions between domain categories (Erwin et al., 2010). Researchers (VH and AD) compared individual card sorts for a third time and discussed to reach a final consensus for their application to the overall theoretical framework.

## **RESULTS**

### *Demographics*

Among the 33 female and male participants in the study, the average age was 40 years (range: 24-58). A majority of the participants were married (67%), lived in rural areas (73%), and had received no more than a secondary education (63%). Additionally, most of the sample was employed full-time (55%). Among the female participants (n=20), 95% reported receiving at least one Pap test in their lifetime, and 75% had received a Pap test within the previous three years.

Total of six themes emerged from the analysis and interpretation of the data related to cultural beliefs about HPV, the Pap test, and cervical cancer. The most prominent themes included the purpose of a Pap test, causes of cervical cancer, fear, embarrassment with the Pap test, community conversations about the Pap test and cervical cancer, and willingness to talk about cervical cancer. Additional quotes associated with each theme can be found in Table 4.1.

### *The purpose of a Pap test*

Most men and women knew a Pap test is associated with being checked regularly for a disease that affects women. Male participants commented more on the frequency of the test, while female participants knew that a Pap test is an exam to check for a vaginal infection. Some participants knew that a Pap test is administered for prevention of disease but, to a lesser degree, that it checks specifically for cervical cancer. One urban female said, “[a Pap test is] to prevent that disease” and one urban male participant said, “every, every once in a while, almost every year, it’s [Pap test] always necessary for women to do a-a Pap exam. Exclusively for women, right?” When clinician participants were asked what their patients knew about cervical cancer, their responses supported what some female participants said: “they [women] have no idea what it’s [Pap test] for or why. Like, their doctor tells them, ‘get it done.’ And, they do it without knowing what for or why.”

### *Causes of cervical cancer*

To assess the spread of misinformation about cervical cancer, female, male, and clinician participants were asked what they or their patients think are the causes of cervical cancer. All participants reported that many community members believe that the Pap test is what causes cervical cancer. Their rationale was that during the exam, the process of collecting cells with a brush scrapes the inside of the vagina causing a wound, and cervical cancer develops as a result. Another common misconception among women was that something was going to be extracted from them, damaging their reproductive organs. One clinician explained what she often hears from patients:



The myths that I've heard [about the causes of cervical cancer] are that a lot of shamans, 'shaman' is what you call the people who work with Andean medicine, umh, they say that the brush from the Pap exam scratches, all of the uterus, they say. It scratches and damages it. They create wounds and cancer develops from there. So they say, 'Why do you think that when they give you a Pap exam, you bleed so strongly? It's because they've given you your wound.' (~ clinician)

Another woman explained what she thought might happen if she were to get a Pap test:

I used to be afraid, to [get a Pap test]. I didn't have a lot of trust. Because, umm, they're doing something regarding the vagina, that's why I used to be afraid. Or, I used to think, in my uterus or, in my vagina, they're doing something, they're taking something out...so that's why I used to think it will wound me. (~ rural female)

Both women and men commented that cervical cancer is caused by poor hygiene, which, after leading to infection, develops into cancer. In the rural areas, additional comments about causes of cervical cancer included working in the fields and exposure to the sun, too many pregnancies, having abortions, wounds in the vagina, poor nutrition, neglect, and not taking care of oneself. Men in urban and rural areas mentioned that cervical cancer was hereditary. One rural male participant said, "I believe [the cause of cervical cancer] is bad hygiene, because it's part of women or —part of a man, too, no? Like, I think that part of, that which is cleanliness or the hygiene of a woman is important, the main thing, for that."

#### *Embarrassment with the Pap test*

Female participants were asked to talk about any times they had experienced embarrassment or shame when getting a Pap test, and if any particular person(s) made them feel that way. Women in urban areas reported they were not embarrassed and recognized that it was necessary for cervical cancer prevention. Others mentioned being embarrassed the first time they received a Pap test, but less so after they were accustomed to it. Many women in the rural areas described feeling embarrassed or ashamed due to the

exposure of their genitals to a stranger, and not wanting their body seen as they felt particularly uncomfortable with male gynecologists. Clinicians commented that women felt embarrassed because, according to sociocultural norms, their husband is the only person allowed to see their body exposed. Some female participants mentioned they heard about the exam from other women in the community who comment about letting someone else see their body. One rural female described what her friends say about getting a Pap test:

We were embarrassed. ‘How can we go to the doctor?’ I was embarrassed having my body seen. I didn’t want it [Pap test]. We’re like that in the countryside. In the countryside we’re, fearful. ‘Ay, how am I going to let them see my body? No, how embarrassing,’ that’s what they say.

One clinician shared her experiences treating rural female patients and said, “the majority of the patients that get embarrassed are patients from the countryside, from the rural area. Because uh, in their culture—they only, the women’s intimate areas have to be seen only by the husband. Nobody else.”

### *Fear*

A common recurring theme from participants was the issue of fear. Many women, specifically in rural areas, were afraid of a number of things related to receiving a Pap test. Some women who had received a Pap test mentioned being fearful because someone other than her husband had seen her body. Others were afraid that the doctors were going to extract something out of their body. They were also afraid of being diagnosed with cancer or, implied that male doctors would physically or sexually harm them. Additionally, women getting a Pap test for the first time heard other women say that is was going to be a painful, traumatic experience. One woman spoke about her experience

during the late 90s when rural women and men in Cusco experienced forced sterilizations in their communities as reasons why they fearfully declined the Pap test:

[I didn't want to get a Pap test because] I thought they were going to hurt me. They were going to put something inside me, I don't know. Because [when the doctors] were coming in that time of Mr. Fujimori, through his time – a person who did curettage came, right? So, my aunts died from that, two died. And I thought, I had that fear in my mind, and perhaps they're going to do something inside of my, my 'this thing', they're going to —they're going to ruin my uterus, and maybe I might get sick. So, I was afraid of that.

(~ rural female)

Clinicians expounded on the fear many women experience: “well, some don't want to get the exam out of fear, no?,—or they're timid, they're very modest. Or, their previous exam was traumatic.”

#### *Community conversations about the Pap test or cervical cancer*

To explore how cervical cancer is treated in conversations within their communities, participants were asked to share what they have heard community members say concerning the Pap test or cervical cancer. Some female participants in urban and rural communities reported hearing that it was beneficial to women's health or that they encouraged other women to get a Pap test. Others heard more negative conversations, some of which included the subtheme of stigma. Women felt judged by people close to them upon receiving a Pap test because they had allowed someone else to see their body. Others induced fear or scrutinized the exam due to the assumption that receiving a Pap test results in physical damage or some kind of extraction from the uterus. Similarly, if a woman was found to have cervical cancer, men and women would call or label her as “dirty”. One rural female said, “those ones [community members] they say, ‘what is that? How? If I'm with only my husband, why am I going to have that disease?’ Another rural female talks about her conversations in the community about cervical cancer:

Some men say, ‘They say that cancer grabs women, ah, since they’re the women who sleep with one man and another. From that, cancer grabs the women.’ That’s how the men talk. Is that true, how is that? The men talk like that. And, other women also believe it. They think that, women, when they have cancer—beginnings of cancer, when they have that, “Yes, it’s that. She’s a dirty woman.”

#### *Willingness to talk about cervical cancer*

Female and male participants were asked about their general willingness to talk about cervical cancer in their communities. This question was asked to assess their comfortability in discussing the topic, and to determine whether there were any reasons why they would not be willing to talk about it. A majority of the participants, female and male, commented that they would be willing to talk to and educate their loved ones about HPV and cervical cancer if they had the proper knowledge about what to say. Other participants commented that discussion is necessary but should be done with caution. Cervical cancer-related issues can be a sensitive, often ‘taboo’, topic that is sometimes not well-received. One urban female said, “I must inform others about the causes, the consequences of that disease. When you do the right exams. Yes [I would be willing].” A rural female community health worker states:

We were trained at Ayni Wasi about that this year, I’m now participating in (things related to) women’s health. In this community I’m learning about that, and I talk about what I learned to the women, about how those things grab us, it’s important, and we way that we must get [the Pap test] done. Aha, and we also distribute our knowledge to the ones who don’t know.

A male participant was willing to discuss it but felt hesitant because of the nature of the topic stating, “if there’s a possibility to converse, I mean, you talk about that, yeah. But if not, like I said it’s not—it’s just that it’s—that’s kind of restricted, yeah.”

Based on the findings from the analysis, each of the six emerging themes was sorted back to the PEN-3 cultural domains in the theoretical framework to determine the

primary domains and associated constructs where future interventions should focus. All six emerging themes, the purpose of a Pap test, causes of cervical cancer, fear, embarrassment with the Pap test, community conversations about the Pap test and cervical cancer, and willingness to talk about cervical cancer either intersected or fell solely into the relationships and expectations and cultural empowerment domains. (Figure 4.1)

Overall, urban participants (men and women) were a lot more knowledgeable about the Pap test and cervical cancer, less embarrassed and afraid, and more willing to talk about cervical cancer with others compared to rural participants. Most of the misconceptions, embarrassment, fear, and negative community conversations connected with the Pap test existed among rural dwelling women and men.

## **DISCUSSION**

This purpose of this study was to explore the sociocultural influences on cervical cancer screening in Cusco, Peru. This study was unique in that it incorporated men into the overall conversation about the Pap test and cervical cancer. This is important in understanding the cultural context because cervical cancer is caused by a sexually transmitted disease (human papillomavirus), and men are involved in the health affairs of women (Nuñez et al., 2016). An example of men's involvement in health care was a comment made by a rural male participant about reasons why women are embarrassed to get a Pap test stating, "only her, her partner should touch her, no? so it's a little—they're afraid or embarrassed."

Urban and rural comparisons were also made to understand cultural similarities and differences between these populations. Responses generally varied based on urban

and rural residence. Urban participants were more knowledgeable about the Pap test and causes of cervical cancer, were less afraid of the Pap test, and had more positive conversations about the topic in their communities compared to their rural counterparts. Education level was also related to cultural beliefs about the causes of cervical cancer and the purpose of a Pap test. Individuals with a higher education were more knowledgeable about cervical cancer and its causes compared to those with less education, and these findings also differed between urban and rural residents.

One salient finding in this study was that participants believed that the Pap test itself causes cervical cancer and is consequently the reason women are not getting or have been afraid to get screened. We found various subsequent issues related to this theme of fear including fear of the exam, fear of the husband, fear of male doctors and fear of the results. Most of these findings are consistent with those of previous studies (Liebermann, VanDevanter, Hammer, & Fu, 2018; Luque et al., 2016; Paz-Soldán et al., 2010).

A comment about the history with former President Alberto Fujimori in this region raised questions about the number of women that mentioned fear of the exam because they would be harmed in some way. It is important to note from a historical perspective that between 1996 and 2000, former President Alberto Fujimori set instituted the National Reproductive Health and Family Planning Program, by which over 200,000 sterilizations of rural women and men occurred throughout the Cusco province (Collins, 2014; Intercontinental.Cry, 2016; Lizarzaburu, 2015). Some areas where these sterilizations took place included districts of the participants in our sample (“REVIESFO Register of Victims of Forced Sterilization,” 2017). During our interviews, women spoke

to us about conversations they have had in their communities about the Pap test, and they made references to being afraid or knowing women who were afraid to get one because they thought something was going to be taken from them. This was the case when women were sterilized, many of them unknowingly, during this time period. That mass sterilizations happened within or among our sample communities might explain some of their references to fear and their misconceptions associated with receiving a Pap test and the idea that the Pap test causes cervical cancer.

Guided by the cultural identity, cultural empowerment, and relationships and expectations domains of the PEN-3 theoretical framework, findings suggest that cultural influences on cervical cancer screening are related to cultural empowerment and the positive, existential, and negative perceptions of the Pap test and cervical cancer when the relationships and expectations of persons in the community nurture, enable or perpetuate these perceptions. These results aligned with previous findings in that participants did not fully understand the purpose of a Pap test, the Pap test was believed to be a painful or traumatic experience, and participants expressed fear and embarrassment upon exposing their bodies during the exam (Erwin et al., 2010, p. 201; Luque et al., 2016; Paz-Soldán et al., 2010).

### *Strengths and Limitations*

This study had several notable strengths. First, researchers were able to access and interview a range of participants throughout the Cusco region, particularly in rural districts where most previous studies in Peru had not explored. Second, relationships with clinicians allowed us to collect information from them to triangulate data gathered from female and male participants thereby reducing researcher bias. Third, the research team

included a native Peruvian speaker of Andean Spanish and an experienced linguist allowing for a rigorous transcription and translation process. A fourth strength of the study is that we had native speaker of Quechua to assist with verification of the monolingual Quechua interviews to strengthen validity of the conversations that were recorded in the native language. The study also had some limitations. Given the high incidence of cervical cancer in Cusco, more female participants than expected reported having a Pap test. While conceptually this could be viewed as a positive outcome, it is possible that social desirability to report an up-to-date screening status could have occurred particularly in rural areas as participants may have felt compelled to participate due to the financial compensation for their involvement. It is important to note that while participants reported having a Pap test, many of their responses also reflected experiences with other women and men in their communities and how they view cervical cancer screening practices. The positionality of the female researchers interviewing male participants about social and gender norms of a disease that largely affects women is also a limitation. Recruitment of men was a challenge in some rural areas of Cusco since many men were not interested in conversing with two U.S. females about cervical cancer. A fully implemented community-engaged approach involving partnerships with male and female community members or health promoters (*promotores*) to conduct the interviews could alleviate participants' discomfort due to gender and nationality differences. It could also extract deeper issues in the community that participants are not comfortable sharing with foreign researchers.



### *Implications and future directions*

In light of the limitations noted with this study, the findings strongly suggest that sociocultural influences may to some degree impact cervical cancer screening uptake throughout the Cusco province. Quantitative studies in testing the same constructs would be needed to validate ascertain the degree to which specific cultural beliefs and the *marianismo-machismo* gender ideologies discussed in this study directly correlate with cervical cancer screening uptake within these communities.

Cultural influences comprised of personal and community beliefs about the purpose of a Pap test, causes of cervical cancer, fear and embarrassment related to the Pap test, and willingness to talk about the Pap test and cervical cancer in the community speaks to the overwhelming need for interventions focused on knowledge and awareness of the Pap test and cervical cancer among women and men in this region. In the case of racial minorities and the cancer experience as a whole, Freeman (2004) concludes that disparities in cancer rates are caused by the interplay of culture, socioeconomic class and poverty, but must also acknowledge the presence of historical social injustices (Freeman, 2004). Matters of cervical cancer and Pap tests might be considered taboo to some and remain undiscussed by others, but most of the participants reported a willingness to talk with loved ones about cervical cancer and HPV under the condition that they were more knowledgeable about the topic. Erwin et al. (2010) suggests strategies to incorporate culture into interventions for addressing cervical cancer screening needs among populations like the one described in this study (Erwin et al., 2010). Increasing the behavioural health capacity and health education in this region is essential to dispel common myths of Pap tests and cervical cancer particularly in rural areas. Moreover,

effective learning necessitates a culturally-sensitive education that acknowledges the historical disturbance of Fujimori and empowers the community to recognize the importance of women's health.

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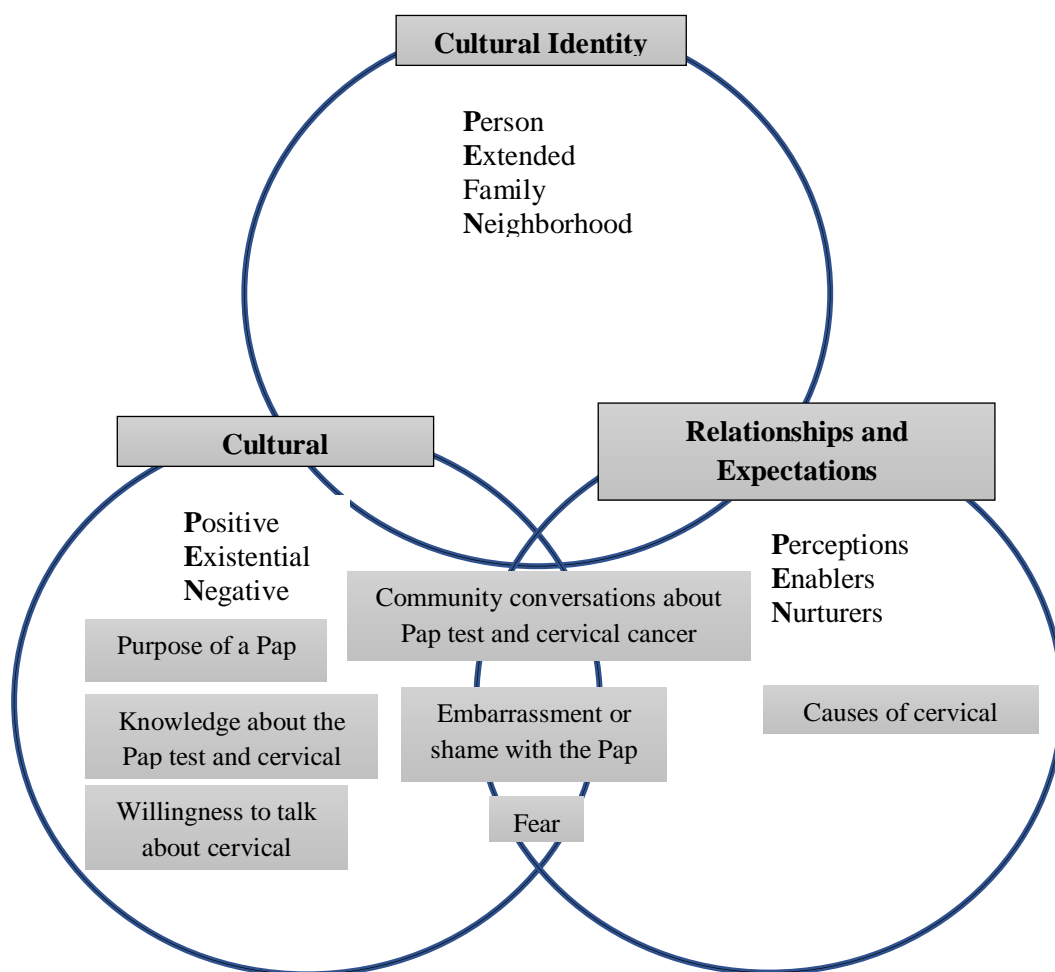
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**Figure 4.1.** Thematic card sort to PEN-3 Framework

**Table 4.1. Cultural beliefs related to cervical cancer screening behaviors**

Theme	Supporting Quote	Group	Location
<b>Purpose of the Pap test</b>	“Sometimes they think and they say, “I have discharge. I have—my foot hurts. My head hurts. And-and I want to—the Pap exam tells me—is going to tell me everything... But the patients from here from the city already know much more. The majority have already gotten a Pap exam before. Uhm, they’re patients who already know...and the come constantly each year to get their check-up because they know what prevention is.”	C	Urban/Rural
	“They have no idea what it’s for or why. Like, their doctor tells them, “Get it done.” And, they do it, without knowing what for or why.”	C	Urban/Rural
	“To prevent that disease.”	F	Urban
	“So you know what sickness you have; infection, inflammation. You have to—according to what the, the doctor tells you, you get treated. So you see—it’s like a treatment. They tell you. It’s that.”	F	Rural
	“To know that you have some infection. Or the start of cancer. We get a Pap exam for that.”	F	Rural
	“Every, every once in a while, almost every year, it’s always necessary for women to do a-a Pap exam. Exclusively for women, right?”	M	Urban
	“A Pap exam I think they get it done once a year, no? Or every three months, or six months per year for women. For breast cancer.”	M	Rural
	“Mmm, mm, mm, for the, for the mother, no? well, ladies, mothers, it’s very important for them to do the Pap.”	M	Rural
	“The myths that I’ve heard are that a lot of shamans, ‘shaman’ is what you call the people who-who work with Andean medicine, uhm, they say that the brush from the Pap exam scratches, all of the uterus, they say. It scratches and damages it. They create wounds and cancer develops from there. So they say,	C	Urban/Rural

<b>Causes of cervical cancer</b>	“What do you think that when they give you a Pap exam, you bleed so strongly? It’s because they’ve given you your wound.”		
	“Here in Cusco they <i>do</i> know that it’s from sexual contact, in the city. But in the countryside they don’t know because they don’t, they don’t have much instruction.”	C	Urban/Rural
	“The cause can be, through this, because maybe, at an early age you’ve had sexual relations. Or you had, maybe, an induced abortion, right? And, it can also be that, you had—hmm, your partner has been promiscuous, right? so then he infects the woman. Or who knows? Maybe the woman is like that too, right? That’s what I have learned about cancer.”	F	Rural
	“No, sometimes it’s born from being dirty mm or it’s in other women, right? Their partners. So it’s raised from those things. And in the heat, right, uh, they walk to the fields with pants, from those things. And then they don’t change their underwear. Ah, or they wear the same thing for the week, no? And from those things, the STIs advance until they become that, that thingamajig, it passes into cervical cancer, right, Ma’am?”	F	Rural
	“I don’t know what —how it happens, but it appears at an older age, an older person, I believe past twenty-five or more is an age, that it happens to women.”	M	Urban
	“Mm, I believe it’s bad hygiene, because it’s part of women or my—part of a man, too, no? Like, I think that part of, of, that which is cleanliness and, uh, or the, or the hygiene of a woman is important, the main thing, for that.”	M	Rural
	“The majority of the patients that get embarrassed are patients from the countryside, from the rural area. Because uh, in their culture, mm in their cu—they only, the women’s intimate areas have to be seen only by the husband. Nobody else.”	C	Urban/Rural

<b>Embarrassment or shame with the Pap test or cervical cancer</b>	“Once they found out about the result, they keep it like a secret. And when we talk around them, “Ayy Miss, don’t talk about that, they’re going to find out.” The embarrassment, they all show it as if they’ll say, “She has cancer.” Or like, it’s not something that –it’s like an embarrassment, nobody can find out about this disease, or that she has can—so, it’s something that I still have to work with a lot. No, she can’t have my colleague from, from work knowing that I have cancer, no? Because the problem is also between <i>them</i> , they say, “Ahh, she has cancer.”	C	Urban/Rural
	“Well, yes, male professionals, no? They reject them. If there’s a male obstetrician or, or doctor, they don’t, they don’t want him.”	C	Rural
	“In-in any case, no?, it’s pretty strange that the most intimate part of a person is seen” [ <i>laughs</i> ]	F	Urban
	“We were embarrassed. “How can we go to the doctor?” I was embarrassed having my body seen. I didn’t want it. . . We’re like that in the countryside. In the countryside we’re, mm, fearful. They don’t want to get—“Ay, how am I going to let them see my body? No, how embarrassing,” that’s what they say.”	F	Rural
	“Only her, her partner should touch her, no? so it’s a little—they’re afraid or embarrassed.”	M	Rural
	“Out of fear of the husband because the husband says, uhh, “If you’re going to be on birth control, you’re going to be with whoever.” That’s what they’ve got them and they make them give birth every year.”	C	Urban/Rural
	“I’m only afraid of the results” [ <i>laughs</i> ]	F	Urban
	“Because I thought they were going to hurt me. They were going to put something inside me, I don’t know. Because they attended—when they were coming in that time of Mr. Fujimori, through his time – a person who did curettage came, right? So, my aunts died from that, two died. And I thought, I had that fear in my mind, and perhaps they’re going to do	F	Rural

<b>Fear</b>	something inside of my, my ‘this thing’, they’re going to —they’re going to ruin my uterus, and maybe I might get sick. So I was afraid of that.		
	“We’re a little afraid of a (male) doctor, yeah.”	F	Rural
	“Yeah, it could be in-in the countryside... Like, here in our communities, <i>machismo</i> still continues. Aha. So, through that they might be afraid.”	F	Rural
	“I used to be afraid, mm, mm, to go. Since, I didn’t have a lot of trust. Because, umm, they’re doing something regarding the vagina, that’s why I used to be afraid. Or, I used to think, in my uterus or, in my vagina, they’re doing something, like, they’re taking something out, no? Mhm, so that’s why, I don’t know, I used to think it will wound me.”	F	Rural
	“Uh...yes I believe that, that would be more when I go to the provinces, the land of my mom, like up to their assembly meetings in—they meet together, and the nurses comes, right, from the health clinic and indicates to them, no? that they have to get that exam. But a lot of women out of fear, dread...sometimes the doctors in the health clinics don’t have that, they’re not more technical, right, sometimes like I have this, what’s it called, how-how do I say this to you—they don’t—they don’t do the exams well because sometimes there are people, women that enter and leave and afterwards they say, “I’m-I’m sick, I’m even more sick as a result of going to the health clinic,” and for those things like that they don’t return anymore, some women.”	M	Urban
	“Ah, well, out of fear maybe the, the partner can’t, can’t tell her, her husband, no? Out of fear that she has it maybe it’s too late already, the – what’s it called? The – the doctor has already seen her but it’s already too late, she already has that cancer. And because of that fear also she can’t tell him, so through—and if she didn’t tell him, there’s no trust in the couple, so the cancer continues advancing, right?”	M	Rural

<b>Community conversations about the Pap test or cervical cancer</b>	“First it’s a topic of taboo or of embarrassment – “You’re talking about private areas, and that’s something you shouldn’t talk about,” It’s – to the point that it seems morbid to them. But, perverseness is more than a simple joke—it’s a little bit of, a comparison to pornography. It’s like only talking about that in a sexual manner, not in a healthy way. Instead they relate it to a sexual part, to sex. To the sexual act.”	C	Urban/Rural
	“Well, now yeah, men, are accompanying their wives, I’ve seen some also that come to ask if her Pap result has arrived yet. It’s changing already a little, the, the education of the men. But, there are still others that, they reject it. “What are you going to get touched for? Why are you going to do that exam when someone gets that exam done, it gives them cancer? Because they’re handled, they’re touched, and that’s the, the cause of cancer.” They have that belief.”	C	Rural
	“I would tell you, everybody says, “Ahh yes, yes it’s important.” But whether they do it, that’s another thing.”	F	Urban
	“Those ones...they say, “What is that? How? If I’m with only my husband, why am I going to have that disease?”	F	Rural
	“...some men say, “They say that cancer grabs women, ah, since they’re the women who sleep with one man and another. From that, cancer grabs the women.” That’s how the men talk. Is that true, how is that? The men talk like that. And, other women also believe it. They think that, women, when they have cancer—beginnings of cancer, when they have that, “Yes, it’s that. She’s a dirty woman”	F	Rural
	“They made me feel bad. Sometimes, they made us scared. “They do it (the exam) poorly; They’re going to do you damage and from that, cancer is going to get you when they scratch you with a scraper,” they say to us.”	F	Rural
	“Mm, “They take out a part of your uterus,” they said something like that, no?”	F	Rural

<b>Willingness to talk about cervical cancer</b>	“No, they talked before, when I was a little girl, because, “They do it like this... They hurt you. They put something inside,” I was afraid from that.”	F	Rural
	“Not really, no really, because that disease isn’t here yet, then, mm, it’s not, it’s not necessary. When it – there was a time, that it did exist [here], then yes I believe that they would. Because we don’t, we don’t, we don’t touch on that topic. Like I told you, it’s not, it’s not necessary [laughs] it’s also not, uhm, in our community. Since we’re healthy, then that’s why we haven’t—we don’t, we don’t talk yet about that...Of course, if when someone, when a professional, uh, makes us understand, of course, we can talk.”	M	Rural
	“I must inform others about the causes, the consequences of that disease. When you do the right exams. Yes.”	F	Urban
	“I think that we need to be very careful to reach out. You need to find the right words to not....maybe hurt other people. Not....not causing them pain nor...more importantly, how can I say it?... make them uncomfortable. To look for the right words.”	F	Urban
	“We were trained at <i>Ayni Wasi</i> about that this year, I’m now participating in (things related to) women’s health. In this community I learned—I’m learning about that, and I talk about what I learned to the women, about how those things grab us, it’s important, and we way that we must get it done. Aha, and we also distribute our knowledge to the ones who don’t know.”	F	Rural
	“If there’s a possibility to converse, I mean, you talk about that, yeah. But if not, like I said it’s not—it’s just that it’s—that’s kind of restricted, yeah.”	M	Urban



“Well, now that I now about those diseases, yes. I’m interested to talk about it with my family because perhaps that don’t know about it.”	M	Urban
“It would be, it would be good. But honestly, almost here in the country we’re not, we’re not used to that...sometimes we leave it to the side.”	M	Rural
Abbreviations: F = female M = male C = clinician Urban/Rural – clinician interacts with urban and rural patients		

MANUSCRIPT 2

THE IMPACTS OF GENDER DYNAMICS ON CERVICAL CANCER  
SCREENING PRACTICES IN CUSCO, PERU<sup>2</sup>

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<sup>2</sup> Haynes, V.E., Brandt, H.M., Friedman, D.B., Simmons, D., Bateman, B.D., Ferris, D.G.  
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## **Abstract**

The goal of this study was to explore the effects of gender dynamics on cervical cancer screening uptake in Cusco, Peru. Semi-structured interviews were conducted among 40 women, men, and clinicians across urban and rural communities. Six themes emerged from the data, including men's knowledge of the Pap test and cervical cancer, men's attitudes toward the Pap test, gender preference of physician, gender ideologies of *machismo* and *marianismo*, and spousal support. Findings suggest male perspectives in rural communities play a large role in women's participation during cervical cancer screenings. Educational interventions concerning cervical cancer should target both men and women in Cusco, Peru.

Key words:

Cervical cancer, Cusco, Peru, gender, screening, qualitative

## INTRODUCTION

Cervical cancer has been on the decline in the United States (U.S.) for many years. It remains one of the top two cancers affecting women in low and middle-income countries (Aguilar et al., 2016; American Cancer Society, 2012). Although the incidence of cervical cancer in Peru decreased over the last 10 years, it is almost four times higher than U.S. rates and nearly two times higher than the worldwide incidence of cervical cancer (Bray et al., 2018; Jacques Ferlay et al., 2010). Similarly, the cervical cancer mortality rate in Peru is almost 10 times higher than that of the U.S. and six times higher than the worldwide mortality rate (Bray et al., 2018; J Ferlay et al., 2018). A primary difference between incidence and mortality rates in Peru compared to the U.S. is the availability and use of cervical cancer screening programs, which are far less available and accessible in low and middle-income countries (Bray et al., 2018; Bruni et al., 2018; Carvallo-Michelena, Luis Rojas-Dominguez, & Piscoya, 2015).

Cervical cancer is caused by a common sexually transmitted infection (STI) known as the human papillomavirus (HPV), which can be contracted via sexual activity by women and men (Petrosky et al., 2015). HPV is one of the most common sexually transmitted infections in the world, but it often goes unnoticed due to the disease's invisible symptoms (Dyne, 2018). A primary risk factor of HPV is quantity of sexual partners (Marín, 2003; Murillo, Herrero, Sierra, & Forman, 2016). Men in South America who are highly sexually active are held in high regard as part of the sociocultural norm however, the praise that this behavior receives increases the probability of passing HPV to a female partner (Marín, 2003; Moreno, 2007). It is important to understand the

sociocultural context and sexual dynamics between women and men in South America for their implications on cervical cancer development across women in the region.

Traditional patriarchal and matriarchal roles are prominent social norms in Central and South American communities (D’Orazio, Taylor-Ford, & Meyerowitz, 2014; Sargent & Brettell, 1996; Stevens, 1973). Not all Latinx individuals uphold gender roles to the same degree (D’Orazio et al., 2014; Nuñez et al., 2016; Torres, Solberg, & Carlstrom, 2002), but it remains necessary to explore gender dynamics and the degree of their impact on cervical cancer screening decision-making and uptake. Contextually, men head the household, and women comply with their husbands’ decisions before seeking health services, particularly regarding cervical cancer screening (Erwin et al., 2010). The South American gender ideology of *marianismo* refers to a woman’s regard for purity, modesty, taking care of the home, childrearing, and submission; *machismo* is a man’s exertion of masculinity, strength, pride, and responsibility to protect and provide for his family (Castillo, Perez, Castillo, & Ghosheh, 2010; D’Orazio et al., 2014; Navarro, 2002). Together, the *marianismo-machismo* ideology refers to patterns of gender norms in social and intimate settings, reinforced by prevailing cultural norms (D’Orazio et al., 2014).

Concerning their sociocultural relevance in cervical cancer screening, sociocultural *marianismo* assumes pure, virtuous women need not receive STI-related screening given chaste women do not engage in such risky behavior. This premise underscores the misunderstandings of cervical cancer and screening practices, further hindering messaging strategies from resonating with women of this mindset (Ashing-Giwa et al., 2004; Fernandez et al., 2009). Similarly, the *machismo* concept works against

the perception of risk in that while women believe they are pure and would have no need for screening, the culture of machismo that praises sexual promiscuity among men, increases the risk of HPV among women. Cervical screening uptake is considered shameful, since it implies a female's promiscuity, and impedes social status in the local Latinx community (D'Orazio et al., 2014). Luque et al. (2016) found domestic violence and disapproval of wives seeing a male gynecologist was of serious concern in certain areas of Peru (Luque, Maupin, Ferris, & Condorhuaman, 2016). Studies on gender concordance with the Pap test showed similar trends for preferring a female a physician for reasons such as fear of spousal abuse if they were seen by a male physician, controlling husbands not wanting their wives bodies seen by another male, and mistrust of a male physician performing the exam without a female present (Erwin et al., 2010; Ince-Cushman, Correa, Shuldiner, & Segouin, 2013; Luque et al., 2016; McAlearney et al., 2012).

Other South American cultural constructs include *falismo* and *hembrismo*, extensions of femaleness, empowerment and gender equality in social relationships (Castillo et al., 2010; D'Orazio et al., 2014; Navarro, 2002). Contrary to empowerment culture, *simpatía* emphasizes avoiding conflict and maintaining harmony. Similarly, *familismo* prioritizes families' needs before females' desires, and *respeto* emphasizes social placement and sexual silence that females experience so as not to negotiate sexual relations with male partners (Ulibarri, Raj, & Amaro, 2012). Arredondo et al. (2008) found that cultural constructs like those previously mentioned were significant predictors of cervical cancer screening uptake particularly among women never before screened, compared to those who did not endorse these ideologies and were more compliant with

screening (Arredondo, Pollak, & Costanzo, 2008). Through empirical testing of measures related to *simpatía*, *familismo*, *respeto*, *marianismo*, and *machismo*, these cultural constructs were found to be highly correlated with each other suggesting that when one construct was endorsed, all others were likewise endorsed (Arredondo et al., 2008). As such, prevailing sociocultural norms pose significant challenges to decision-making around cervical cancer screening, making compliance with screening recommendations much less likely.

Studies that acknowledge the role of *machismo* in Latinx populations identify the need to include men in educational campaigns concerning sexual and reproductive health, including cervical cancer (D’Orazio et al., 2014; Erwin et al., 2010). Incorporating men has implications for the development of cervical cancer screening messages that incorporates traditional Latinx values and positions screening in a cultural frame for men and women (Spina, Arndt, Landau, & Cameron, 2018). Gender and power dynamics between men and women situated in the sociocultural context of Peruvian life have been among the recommendations for next steps to inform contextually and culturally appropriate cervical cancer interventions (Diaz et al., 2015; Weaver, Geiger, Lu, & Case, 2013; Williams-Brennan, Gastaldo, Cole, & Paszat, 2012). The current study examined the role of gender dynamics on cervical cancer screening behaviors within urban and rural communities of Cusco, Peru. Understanding how gender roles impact cervical cancer incidence and mortality among women in Cusco is crucial to increase regional cancer screening rates via health campaigns and interventions.

## **MATERIALS AND METHODS**

### *Research sample*

Participants were recruited during two months in 2018 throughout urban and rural areas of Cusco, including local clinics administering Pap tests and other surrounding communities. In the clinic setting, women were invited to participate in the study after receiving a Pap test. Any male accompanying his female partner or family member to her appointment was also invited to participate. Male and female participants not seeking services through a clinic were recruited from commonly used community areas (e.g., markets, taxi service locations, town plazas). Clinicians were also invited to participate during times that did not interfere with patient care.

Urban and rural comparisons displayed variation in participants' knowledge of cervical cancer prevention and detection. Inclusion criteria for men and women required they were age eligible or had a partner or family member who was age eligible to receive a Pap test. Age eligibility was between 25 and 60 years old in line with the Peruvian Ministry of Health (Alcalde-Rabanal, Lazo-González, & Nigenda, 2011). Women outside the 25-60 age range or who did not wish to participate without their partners present were excluded.

### *Data collection*

Interview guides were pilot tested in Spanish and Quechua (when applicable) with females and males to ensure questions were clear and to determine the need for inclusion or exclusion of certain questions and probes necessary for the conversation (Lunsford, Ragan, Smith, Saraiya, & Aketch, 2017; Ragan, Lunsford, Smith, Saraiya, & Aketch, 2017). Guides were slightly longer for women and included questions related to



knowledge of HPV, cervical cancer, and the purpose of a Pap test. Questions elicited their personal experiences receiving a Pap test and any community conversations they witnessed or participated in related to the Pap test. The male interview guide was structured similarly, inquiring about their knowledge of HPV, the Pap test, cervical cancer, and their perspectives on related community conversations. Both interview guides included an overview of HPV, its relation to cervical cancer, the importance of screening, and suggestions for when to get screened. This was read to each participant in the beginning of each interview. We asked clinician participants about issues they witness with HPV and cervical cancer among females, their encounters with males concerning the Pap test and cervical cancer, and conversations they have with their patients. Interviews were conducted in Spanish or Quechua by a linguist specialized in the Andes and trained on the study protocol.

Under the approval by the University of South Carolina and PRISMA, the Peruvian Institutional Review Boards, a total of 39 interviews were conducted with 20 females, 13 males, and six clinicians. Interviews were conducted until saturation was reached, that is, until no new information was elicited from the participant groups (Creswell, 1998; Strauss & Corbin, 1990). An informed consent form explaining the project was provided in participants' preferred language (i.e. Spanish, Quechua), and signatures indicating a willingness to participate were obtained prior to the interview. Interviews lasted approximately 40 minutes, and each participant received S./20 Peruvian soles (approximately \$7 USD) for their time.

### *Data Analysis*

As data were collected, recordings were de-identified, transcribed verbatim in the language of the recording (i.e. Spanish, Quechua), and translated into English. A native Quechua speaker (YZ) reviewed Quechua transcripts for accuracy before they were translated into English. Two research team members fluent in Andean Spanish (BB and KN) cross-checked the Spanish transcriptions and their English translations for completeness, accuracy, and contextual interpretation.

The initial codebook was developed by hand based on provisional coding from the interview guide. The next iteration of the codebook was established from hand coding the first two female and male interview guides. To minimize bias of personal interpretation of the initial coding scheme, four female (two urban and two rural) transcripts, four male (two urban and two rural) transcripts, and one clinician transcript were coded followed by an independent review of them by a second reviewer. Differences in coding were resolved between the coders, and remaining transcripts were coded using this coding schema during the first cycle of the coding process. This set of transcripts was reviewed against the second draft of the codebook. Once the coding schema was determined, all codes were entered into NVivo® 11 Plus (QSR, 2010). Subsequently, a codebook was generated in Nvivo from the codes entered and underwent four revisions before the final version was determined. An interpretative phenomenological analysis was conducted from coding and confirmatory card sort discussions that synthesized and collated smaller themes into broader categories. Interpretive phenomenological analysis is the process of highlighting and examining a participant or group of participants' lived experiences related to a particular phenomenon

under study – in this case cervical cancer screening uptake and the gender dynamics that transpire around the screening (J. A. Smith & Osborn, 2015; J. Smith, Flowers, & Larkin, 2009). Confirmatory card sorting was used between researchers to verify the direction of the lead researchers' synthesis of topics that emerged from the transcripts into broader themes (LeCompte, 2000; Waite, 2011). After independent coding by two researchers (WZ and VH), confirmatory card sorting (HB, AD, and VH), and an interpretive phenomenological analysis, six themes emerged related to gender roles and men's attitudes concerning their partners or family members, the Pap test, and cervical cancer.

## RESULTS

Among the 33 female and male participants, all spoke Spanish save four female Quechua-speaking participants. The average age of females was 42 years, and 36 years among male participants. Most female participants were married 80% (n = 16) while most male participants were single or cohabitating 54% (n = 7). Just over half of the female participants had not studied beyond primary (elementary) school 55% (n = 11), compared to 79% of the male participants who had finished secondary school (middle and high school) or higher (n = 12). Of the sample, most females and males worked full time (55%, n = 18).

Six prominent themes related to gender roles and cervical cancer screening emerged from the interviews: 1) men's knowledge of the Pap test and cervical cancer, 2) men's attitudes toward the Pap test, 3) gender preference for exam administration, 4) *machismo*, 5) *marianismo*, and 6) spousal support. Additional responses for each theme related to gender dynamics and cervical cancer screening can be found in Table 4.2.

### *Knowledge about the Pap Test and Cervical Cancer among Men*

When male participants (n = 13) were asked about what they or other men in their community know about the Pap test and cervical cancer, just over half (n = 7) of them claimed to be aware of general information (e.g., that cervical cancer is a disease affecting women), while the remainder (n = 6) knew nothing at all. According to one rural male participant, “In the city, I feel like there’s already there’s a little information, but I believe there isn’t clarity. There isn’t clarity because they do know that there is a problem of cancer, but they don’t know the cause... they only say cancer in the woman, right.” Another rural male participant said the following about Pap test and cervical cancer education:

They’re totally uninformed about all that. At least, the ones from the health centers and the government, the regional government, and the municipalities, they don’t...they don’t have the capability to support these communities that are uninformed about all the diseases that women have.

### *Men’s Attitudes toward the Pap Test and Cervical Cancer*

Female, male, and clinician participants were asked about what they have heard men say regarding the Pap test and cervical cancer and whether they knew any men who did not support women getting a Pap test. A range of perspectives emerged from all three groups. The most prominent responses characterized men as dismissive and sceptical, asserting also that men do not view women’s health as a priority. Male participants reported that some men avoided the conversation while others found it to be important. One urban male participant stated, “Men are mostly closed to that type of conversation.” A clinician also said this about her experiences with men she encounters:

Well, now yeah, men, are accompanying their wives, I’ve seen some also that come to ask if her Pap result has arrived yet. It’s changing already a little, the, the education, of the men. But there are still others that reject it [the Pap test]. “What

are you going to get touched for? Why are you going to do that exam which, when someone gets that exam done, it gives them cancer? Because they're handled, they're touched, and that's the, the cause of cancer." They have that belief.

### *Gender Preference of Physician for the Exam*

Female and male participants were queried regarding any preference for the gender of the clinician administering the exam. A majority of the female and male participants said they prefer or, in some cases, would only allow a woman to perform the Pap exam, i.e. gender concordant care. Reasons for wanting only a female clinician included the idea that women felt more comfortable with other women due to anatomical similarities, fearfulness of a male physician, and men's skepticism of other males (clinicians) touching their wives' bodies for fear they would be abused in some way. A rural female participant stated, "We're [we women are] afraid of a male doctor." Likewise, a rural male participant said, "They [people giving the Pap test] always have to be women." While women and men in rural communities tended to have a similar mindset about who should perform the Pap test, this urban male participant provided a personal and confirmatory perspective about gender concordance:

Well...uh...for me it would be, it can be a man or a woman [gynecologist], no? Here in the city it's normal, but not in the country. Because uh, the men [in the country] want the Pap to be [done by] strictly women, the gynecologists. No, no, they wouldn't accept another man touching his woman.

One clinician participant explained why some men only want female clinicians for their wives' exams, "In the countryside, it's more than anything to prevent that it might cause more damage to his wife. They're much more afraid now of their intimate parts being touched. For them it's bad, they don't-don't want it."

## *Machismo*

Findings related to the theme of *machismo* were prompted by questions concerning men's roles in women receiving Pap tests, women's fears of receiving a Pap test due to their husbands, and men's opinions of the Pap test and cervical cancer. In some instances, the topic arose in other conversations during the interview discussing spousal support or men's attitudes. The urban/rural distinction was a key factor that elicited divergent responses regarding the role of *machismo* in Pap test uptake. Many participants acknowledged that rural women are less inclined to obtain a Pap test in such areas where *machismo* prevails. Additionally, participants made clear distinctions about which residential areas they tended to experience *machismo* the most. The Spanish term *machista* refers to male chauvinist behaviour and is derived from the Latin American gender ideology of *machismo*, which is defined by male dominance and/or male superiority over women. One urban male participant shared his perspective about his family and community, "I had a grandfather that was very *machista* and he didn't allow my grandmother to go to the health center. In my case, I would want my partner, my sisters who are already older, to do it [the Pap test], no? That would be for me but, since in Cusco the majority—the men are *machistas*." Several rural female participants mentioned their experiences facing *machismo* in their communities. One rural female participant said the following:

Sometimes, some men are *machistas*. They mistreat us. From that [Pap test] too, physical mistreatment. and sometimes some men [clears throat] – they have another woman, another one, and from that sometimes—he brings us the sickness, when they're with another woman.

Clinician participants also shared their experiences dealing with the culture of *machismo* with their patients. One clinician participant who treats urban and rural females said the following about trying to encourage women to get a Pap test:

In the zone of Canascanchis, which is beyond Urcos, husbands must give permission to their wives, so they get the Pap exam. Most of the countryside, of the communities, the husband must give them permission. If the husband tells them, “I don’t want it,” they don’t get it.

### *Marinismo*

Themes related to *marianismo* were generated from responses about related to *machismo*. The theme of *marianismo* also came up in conversations related to fear or having lack of spousal support. One urban female participant hinted at her experiences talking with men in her family about the Pap test and cervical cancer, “So sometimes when they cut you off their conversation, it’s better not to say anything else.” According to one rural male participant, women are fearful, “because they’re a little afraid of men, no? Sometimes – a lot of things could also happen.” A rural clinician participant provided this similar reason for why women do not feel empowered to seek Pap tests and other health related services:

They can’t talk about sexual relations. The woman is only there to please the man when he wants. That’s why there’s a lot of domestic violence. There a quite a bit of sexual violence. And since the women don’t have any education, they’re quiet, they’re submissive, they’re only there to attend to whatever the husband says.

### *Spousal Support*

Participants were asked to share their perspectives on spousal support for the Pap test and, when necessary, follow-up care in the case of abnormal test results. A range of responses were observed across participants in urban and rural areas. One rural male

participant said, “He must go to the doctor, right? Of course, support, [getting a Pap test] because sometimes, uh, I think, the best support sometimes, is moral support and by taking her to the doctor.” Similarly, an urban female participant reported, “He [my husband] also tells me, ‘Well, you have to do everything you can, what else can we do? Your health comes first.’” A clinician participant said the following about observed differences in spousal support in communities:

Here in the urban zone, the man’s role is more shared with the woman’s role. There’s a little bit of everything [support]. As much as there are men who worry a lot about their wife’s health, they’re very interested in receiving the Pap exam, they accompany them, and by their side, they caress them, they tell them, “Yes, we’re going to come back for the results.” They themselves come and ask how their wife is, they get happy with them if it’s [the Pap test] negative, as much as there are also men who never accompany them, and there are also women who say that, “I’m coming secretly, he doesn’t even want me to be checked.”

For most emergent themes, clear urban and rural differences were observed related to gender dynamics and perspectives about the Pap test and cervical cancer. Many females and males in the rural communities had more cynical views about the Pap test and cervical cancer compared to their urban counterparts. Observed differences reflected some of the reasons why women, particularly in rural communities, may not feel empowered to get screened.

## **DISCUSSION**

Inquiry into men’s knowledge of the Pap test and cervical cancer was a means to explore sociocultural beliefs about these topics from female and male perspectives. These conversations require communication between women and men about sexual transmission of a disease and the exposure of a female’s body for the Pap test for



screening and prevention. In the context of Latin American culture, these conversations can be influenced by the *machismo-marianismo* gender dichotomy which consequently impacts women's decision-making for screening, regardless of their knowledge base about the Pap test and cervical cancer (Moreno, 2007; Torres et al., 2002). Results from the investigation of gender dynamics between women and men in Cusco, Peru on cervical cancer screening uptake uncovered six primary themes. These included men's knowledge of the Pap test or cervical cancer, men's attitudes toward the Pap test, gender preferences for the exam administrator, *machismo*, *marianismo*, and spousal support.

Despite the self-reported lack of knowledge about the Pap test and cervical cancer, men recognized the topic of cervical cancer as important and wanted more information to take back to their communities. Clinician participants likewise acknowledged the impact of *machismo* on women's Pap test uptake due primarily to the absence of information about Pap tests and cervical cancer. Clinicians also mentioned that, as men become better educated on the topic, they are seeing more spousal support and more women feeling empowered to get a Pap test. Regarding perspectives of men's attitudes toward the Pap test and cervical cancer, most female participants in urban and rural areas perceived men as having a negative or dismissive attitude, whereas men in urban, and even some rural areas, were supportive of it. This mixed trend was also similar to the findings of spousal support for Pap tests, although reports of the lack of spousal support occurred primarily among women in rural areas. Comments from clinician participants also confirmed these differences in gender and residential perspectives based on their interactions and locations of the patients they served.

Similarities between female and male participants were such that most preferred gender concordance, in this case a female clinician, to provide the exam since women were purportedly afraid of men, and men did not want other men touching their women. This finding is consistent with other studies among women in Central and South American communities where women were afraid to be seen by a male physician due to controlling or abusive spouses (Erwin et al., 2010; Luque et al., 2016). However, there were several instances where male participants referred to the idea that something traumatic or dangerous might happen with a male clinician, such as abuse or damage to a woman's body thus, direct accounts of male preferences for a female clinician may have been for protective reasons and not necessarily always associated with negative *machista* behaviors.

Regarding specific *machismo* influences, all participants drew distinct differences between urban and rural areas where *machismo* had a direct impact on the decision-making of women to get a Pap test. Clinician and female participants referenced some women as silent in the presence of men, submissive, and located in situations of physical and sexual abuse from their husbands. These findings closely align with the quantitative predictions from Arredondo et al. that there is a lack of cervical cancer screening among women who experience *machismo* compared to those that screen regularly (Arredondo et al., 2008). It is important to note that in the rural areas, there was substantial overlap between the themes of *machismo* and men's attitudes (negative), gender concordance for the Pap test exam, *marianismo*, and lack of spousal support. Collectively, these findings contribute to research suggesting the need to examine gender roles and sexual beliefs as they relate to cervical cancer (D'Orazio et al., 2014).

Examining the *machismo-marianismo* gender ideologies in Cusco, Peru provided insight into the sexual dynamics, particularly in rural areas, that have a direct effect on the healthcare of women in these communities and where cervical cancer-related interventions should be targeted. While machismo does in fact exist in various communities, it cannot be generalized to all men in South America or Peru. This study identified men in urban and rural areas that are in fact supportive of women's health and would be inclined to be more included with increased knowledge about topic of cervical cancer. An important facilitator of increased spousal support would be the inclusion of men in cervical cancer screening education interventions, honoring the patriarchal head and influence on healthcare decision making among women throughout this region.

#### *Strengths and limitations*

This study had a few limitations worth noting. First, there were no male clinicians that provided Pap tests during the time of data collection with clinician participants in this study. A male clinician perspective would have enriched our findings about the gender preference for the Pap test administrator and would have further triangulated reports from the female and male participants. It was difficult at times to recruit males in urban districts to discuss a health topic that affects women. Taking into account that two female researchers led the study, this could reflect prevailing norms related to gender concordance concerning a woman-centric issue. While we are unsure of the degree to which this was the case, other factors that may have contributed to recruiting males such as lack of communication, knowledge, feelings of inferiority or superiority toward female American researchers, power dynamics, or work day interference. To alleviate these barriers, engaging and training community health promoters, especially men, to engage in

these conversations might prompt more detailed information about gender roles and cervical cancer prevention. Another limitation was that men may not have understood the full process involved with a Pap test. This may have resulted in some men responding to information that they knew only superficially about a Pap test without having full knowledge of the procedure. Further, research will be needed to better explain in detail what a Pap test involves, what it means, and how men feel about an invasive procedure given that the topic itself is not widely discussed.

Despite these limitations, the study had several notable strengths. The inclusion of men in the study was unique in that most studies that touch on issues of gender dynamics only engage perspectives of women (Liebermann, VanDevanter, Hammer, & Fu, 2018; Nuñez et al., 2016). Additionally, incorporating clinician perspectives to triangulate what male and female participants reported about *machismo*, *marianismo*, spousal support, and men's attitudes of the Pap test helped provide a well-rounded perspective on the issues that were identified in urban and rural communities.

#### *Implications and future directions*

Acknowledging the role of men in sexual health interventions is a means to break down one of the sociocultural barriers that impede cervical cancer screening. By involving men, educational efforts can be bi-directional within male-female dyads thereby increasing the likelihood of approval of screening and prevention of both parties. Moreover, when men are involved in educational efforts to the same degree women are, they can in turn become a positive support system in the event of an unfortunate screening outcome, or a resource for a reminder to maintain regular screening uptake. Educating men on sexual health and reproductive topics is a means to integrate

sociocultural norms. This empowers women to prioritize their health, not despite their matriarchal role in the family, but as an effort to positively sustain it. In the long term, this is an important recommendation to increase screening rates and decrease cervical cancer mortality.

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**Table 4.2. Participant quotes related to gender dynamics and cervical cancer screening**

Theme	Supporting Quote	Group	Location
<b>Knowledge about the Pap test and cervical cancer among men</b>	“About cervical cancer, I don’t know much about that. Because people mostly...well, forgive me but here in-in Peru they’re ignorant about that type of-of information, no? And almost nobody knows about those issues.”	M	Urban
	“Not really, because that disease isn’t here yet - it’s not necessary. There was a time that it did exist here. But, like you say, in order to prevent, to take preventions, right, because now already we from the communities we migrate, one nowadays migrates. So, it would be so important, uh, to touch on that—that topic in the community.”	M	Rural
	“Mm, strictly by the name no, they only know it with other names, like ‘infection’ or, ‘infections for the woman.’ ”	M	Rural
	“I think they’re little informed. Information is lacking.”	M	Rural
<b>Men’s attitudes about Pap test and cervical cancer</b>	“Here in the city, if some man told his wife not to receive treatment, we see it to mean he doesn’t care. He’s simply not interested in the health of-of-of his wife. But in the countryside, it’s more that it-it might cause more damage to his wife. They’re much more afraid of their intimate parts, uhm, being touched. For them it’s bad, they don’t-don’t want it. They don’t want it because they think that it’s going to be damaging them much more. They-they have the belief that all the healing has to be on the outside. Not from inside, there’s no reason to touch them.”	C	Urban
	“Well, now yeah, men, are accompanying their wives, I’ve seen some also that come to ask if her Pap result has arrived yet. It’s changing already a little, the, the education, of the men. But there are still others that reject it. “What are you going to get touched for? Why are you going to do that exam which, when someone gets that exam done, it gives them cancer? Because they’re handled, they’re touched, and that’s the, the cause of cancer.” They have that belief.”	C	Rural

	“Sometimes, when you talk to them, “ <i>This-these are the causes of this disease,</i> ” like that, when I know; and sometimes they say, “ <i>Nah! That’s nonsense,</i> ” like this they say. Then that is why it’s hard to talk to men. There is no confidence to speak to men, but with women yes.”	F	Urban
	“They don’t place any importance on it, nothing, no! They only laugh, nothing else!”	F	Rural
	“...about the Pap exam, men don’t really say anything, just, “Are you well or no?”, that’s all our husbands want to know, “Are you well or no? Are you okay, or what might you have?” They just want to know that. Eh, they say that, “What is that disease? What would be in my woman? No, that’s not there.” because they think there are some women that are with more than one man...So, they say that she’s not with anybody else so, “She’s just with me.”	F	Rural
	“...it’s transmitted through sexual relations. It could be, right? that the woman here would suspect, right? That the man deceived her. Maybe he’s been with another woman...he got infected and passed it on to her. It’s that, I think more than anything a woman would think those things...she going to think why it’s transmitted?”	M	Urban
	Uh, I believe that in reality, in the way that they—uh, men already know a little about the—about the Pap exam, they do take it as important. They do say that the Pap exam is important.”	M	Urban
	“...she would consult me first, right, if she’s going to do that, and I would tell her, “Let’s go,” I accompany her and we get the exam, right?”	M	Rural
<b>Gender Preference of Physician for exam</b>	“Yeah, it doesn’t matter.”	F	Rural
	“Not a man. Only a woman [ <i>laughs</i> ]”	F	Rural
	“Because you hear in the news that they killed a gynecologist for, for doing that case, right, for touching his woman without him giving his consent, no?”	M	Urban

<b>Machismo</b>	“Mm, I think that, here in the country we have that reservation [about the Pap test]. That timidity of having, uh, a male person, he might touch her body.”	M	Rural
	“Because they’re a little afraid of men, no? Sometimes—a lot of things [abuse] could also happen.”	M	Rural
	“In the rural areas, uh, out of 100%, 5 or 6% know about this [Pap test] and that and the husbands agree that their wives get treatment and contraception. But the other great majority, no. They’re very <i>machista</i> .”	C	Urban/ Rural
	“They think that when they took out the uterus they can’t have them anymore, not even for sexual relations, no?, she’s no good for that anymore. They believe that, that if let’s say, she needs an operation or a surgery, the woman will be invalid, she’s going, she’s going to remain in bed, she’ll no longer be able to work in the field, she’s not going to be able to do the work that, that is done in the home. No? “So, why should she be invalid, no, I don’t want her to get cured or treated. They have that idea.”	C	Urban/ Rural
	“In the countryside, there’s a lot of <i>machismo</i> . The men, some support. And some don’t. Some have the idea that they’re going to damage their wives. So the men do—the women can’t talk about sex. They can’t talk about sexual relations. The woman is only there to please the man when he wants.”	C	Urban/ Rural
	“Well, in Cusco they are very <i>machistas</i> . Because the first thing they say for example, “if she has gotten that cancer is because she has had an infection. I don’t know who she’s been with.” The bad thing is that they talk like that, saying “Probably she’s been with many men and she got herself infected,” but it’s not like that.”	F	Urban
	“Over there in the communities their husbands drink. When they’re pregnant, they don’t even help them do anything. When you have to come to get check-ups at the health center, when you’re pregnant, but some men don’t want it. No. They don’t care about that. And they hit their wives! “How are you going to go to the health center? You’re not embarrassed of having your body seen?”	F	Rural



	“Yeah, it could be in-in the countryside. Like, here in our communities, machismo still continues.”	F	Rural
	Now there’s no longer fear—before yes. Before they were afraid of their partners—they used to drink and they used to hit them. They had children, mm, little ones, but not now, not now since now we’re already, a new generation so now they realize, they don’t drink like that sometimes, like my age, they have just one child, more than anything it’s just, they have just two, three, four kids not like before they would have a dozen, ten or so, not anymore.	F	Rural
	“There’s more in the community, there’s machismo. The men believe more that, owner of the woman and they don’t let the women get that Pap exam done. Like for example, when they hit them, when they yell at them. They don’t let them even tell their friends, or any other people, they don’t let them. And, they think that when she goes to get the Pap exam, she’s going to tell everything. She’s going to have her body seen. That’s what they think, the men.”	F	Rural
	“But there are some who don’t know or, or maybe they don’t get it, they c—they can’t get it or they prohibit it sometimes because of <i>machismo</i> , too, there’s a lot of <i>machismo</i> . It’s that sometimes they, mm, where, where they say, “No”, uhm, they give commands at home. Why do I tell you this? Because sometimes also, like I told you, it’s <i>machismo</i> that sometimes, “Why didn’t you tell me?”, like so, right? he tells his partner off.”	M	Rural
<b>Marianismo</b>	“So when we ask the patient, “Age? How old are you?” Uhm, “When did you get your period?” The woman is cowering and the one who answers is the man. There are some zones around—mmm, around Quiquijana, the communities of Ccapcca, upper Ccapcca lower Ccapcca the men are the ones that talk. Not the women.”	C	Urban/ Rural
	“The husband knows when the last child was born, the husband knows his wife’s ID number, or like, the husband knows everything. And she many times doesn’t say anything. In rural zones, the woman enters and she remains quiet, and the one who responds is the husband.”	C	Urban/ Rural

	“He’s <i>machista</i> and, and sometimes they see it—well they’re like beasts that, you see the woman they don’t understand it, they don’t live it like so, in their own skin. And if the women is a little submissive, quiet—it’s like, traumatized, right? by the husband – so, you forget about yourself. And for those things too, no?”	F	Urban
<b>Spousal or partner support</b>	“So to speak in Cusco, yes there are many partners that come here accompanied by their husband, to gynecological visit, to the Pap exam. The husband knows, he has knowledge that the Pap exam is important. Others, uh, assimilate to it very slowly, others simply say, “Ah, that’s silly. She’s not going to die.” Yeah, the ones from the countryside. And they wait until they die.”	C	Urban/ Rural
	“Eh...well, I’m going to tell him, my husband but...sometimes he’s in like I told you, because of work – because my jo—mm, my husband is, uh, a carpenter – so his work is tiring, heavy. And, sometimes, he goes off to work, he comes back tired, he falls asleep, and sometimes there’s not even time to think that the disease, no? And I also can’t overwhelm him.”	F	Urban
	“He has always been supporting me, right? Even today he came with me.”	F	Urban
	“He’s not really interested if you’re well or you’re unwell. He’s not interested. But I do that sometimes with my own money. He doesn’t tell you, “Hey, take this,” you know, “I’ll give you 10 soles,” or however much, “and go get it done,” or “Let’s go, so they’ll give it to you.” So, uh, from that part I feel a little abandoned.”	F	Rural
	“My husband also supported me in that. He’s told me, “Go. Do it—you might be unwell. And how are we going to know if you’re unwell or not? You have to get yourself seen.” He’s told me like that.”	F	Rural
	“For that exam, yes I completely agree that they do it. I insist, yeah.”	M	Urban
	“No, actually I would tell my wife, “Do the exam so you don’t spread it to me.”	M	Urban

	<p>“Well, mm, I, as her husband, since I—since I love her, then I should be worried about her health. So, I should search, no? But I’m not like – I’m not like that. So, honestly – and also conversing with the partner, right? So, now maybe if she wants to ok then, and how that’s played out; yeah seeing as they – if we – if, if she doesn’t want to, I can’t make her do it either without her consent. Mhm. That—for one thing she’s that, the owner of her body. So, she is the one that has to make the decision. From me just, yeah, I just have to support her is all.”</p>	M	Rural
	<p>“Well, the truth is, with that like I told you, we’re not used to it.”</p>	M	Rural
<p>Abbreviations: F = female M = male C = clinician Urban/Rural – clinician interacts with urban and rural patients</p>			

MANUSCRIPT 3

UNDERSTANDING COMMUNITY PREFERENCES FOR  
INFORMATION TO INCREASE CERVICAL CANCER KNOWLEDGE  
AND SCREENING IN CUSCO, PERU<sup>3</sup>

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<sup>3</sup> Haynes, V.E., Brandt, H.M., Friedman, D.B., Simmons, D., Ferris, D.G. (2019)  
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## **ABSTRACT**

Studies conducted in Latina communities throughout Peru have identified lack of knowledge about the Pap test and cervical cancer as a contributor to the disparity of cervical cancer incidence and mortality. Knowledge about cervical cancer screening is an essential first step to decrease the incidence and mortality of the disease. In an effort to address the limited knowledge about cervical cancer in the Peruvian region, one-on-one semi-structured interviews were conducted with 20 females, 13 males, and six clinicians across urban and rural communities of Cusco, Peru. Four categories of themes emerged from the data including: knowledge of HPV, the Pap test, and cervical cancer; preference for communication channel; interpersonal communication; and preferred message content. Patient-provider communication was among the top preferences of participants to receive information about the Pap test and cervical cancer. Workshops, trainings, and direct personal communication with trusted community members were also popular channels desired by rural females and males in this study. Participants in urban areas preferred internet, radio, TV, and other written materials for information only secondary to patient-provider communication. While interpersonal communication with doctors was preferred, clinicians' availability may be limited. Training of community advocates by physicians and nurses is a means to develop reliable sources to disseminate information into communities when access to a health center is not feasible.

## INTRODUCTION

Cervical cancer continues to be a significant health challenge for women in low and middle-income countries (LMICs), including Peru (Aguilar et al., 2016; Bray et al., 2018; Bruni et al., 2018). The incidence and mortality of cervical cancer in Peru is twice the worldwide rates of cervical cancer, despite decreases over the last 10 years (Bray et al., 2018; Ferlay et al., 2010). While these disparities have been shown to be a result of structural, socioeconomic, and psychosocial barriers, lack of knowledge about HPV and cervical cancer has remained a prominent factor despite intervention efforts to address these barriers. Previous studies conducted in Peru have identified lack of knowledge about the Pap test and cervical cancer as a significant contributor to the disparity of cervical cancer incidence and mortality in these areas (Ferris, Condorhuaman, Waller, & Lilienthal, 2015; Han et al., 2012; Lee, Paz-Soldan, Carcamo, & Garcia, 2010; Winkler, Bingham, Coffey, & Handwerker, 2008). Thus, knowledge about cervical cancer, particularly screening via Pap tests, is an essential first step to decrease the incidence and mortality of cervical cancer among Peruvian women.

Health communication strategies can be used to address knowledge gaps related to cervical cancer through various channels. Communication channels are formally defined as the mode for which a message is delivered such as mass media (e.g. TV, radio, newspapers, magazines, posters, and videos), interpersonal communication (e.g. family, friends, physicians, personal networks) or events (National Collaborating Center for Methods and Tools, 2010; Oetzel, Vargas, Ginossar, & Sanchez, 2007).

Communication channels are important to consider in the development of health communication campaigns to ensure that the target audience has access to the channel,

and so that messages can be disseminated to large audiences (Wakefield, Loken, & Hornik, 2010). The Community Guide to Preventive Services is a compilation of evidence-based interventions and communication recommendations from the Community Preventive Services Task Force on a variety of health topics. The goal of The Community Guide is to provide information on preventive programs, services, or policies that have evidence of success and provide suggestions for application in communities. Within The Community Guide are recommendations for communication channels that have been shown to be effective for increasing behavior change for cervical cancer screening among U.S. women (“Guide to Community Preventive Services. Cancer Screening: Mass Media Targeting Clients – Cervical Cancer,” n.d.). An example of the application of these evidence-based recommendations is the implementation of the *Inside Knowledge* campaign by the U.S. Centers for Disease Control and Prevention (CDC) for gynecologic cancer awareness. The *Inside Knowledge* campaign makes use of both small media (e.g. posters, brochures), mass media (e.g. radio, and video public service announcements) and interpersonal communication channels for dissemination to a variety of audiences (Centers for Disease Control and Prevention, n.d.; Rim, Polonec, Stewart, & Gelb, 2011). The *Inside Knowledge* campaign is a practical example of health communication interventions to address cervical cancer awareness and knowledge across the U.S. other countries have used Health communication channels such as videos, movies, TV, healthcare providers, or a combination of channels to address HPV and cervical cancer knowledge and awareness (Abiodun, Olu-Abiodun, Sotunsa, & Oluwole, 2014; Mueller et al., 2012; Wakefield et al., 2010). In an effort to address the burden of cervical cancer in Latin America, the Pan American Health Organization (PAHO) released a

communication campaign in the fall of 2018 to promote cervical cancer awareness and provide information to women, girls, and healthcare providers about cervical cancer prevention (Mitchell, 2018). Studies that have implemented health communication interventions in Peru specifically, have consistently documented the importance of community engagement in the process of developing health communication messages and the use of patient-provider communication as a communication channel in the provision of cervical cancer screening and education (Bayer, Nussbaum, Cabrera, & Paz-Soldan, 2011; Luque, Opoku, Ferris, & Guevara Condorhuaman, 2016). As an example of community engagement, and interpersonal communication, research that tested the impact of video interventions with community health workers has shown a significant increase in knowledge about cervical cancer and procedural expectations. (Luque, Tarasenko, et al., 2016).

Berkman et al. (2000) highlights the role of social relationships on health outcomes and the importance of social ties that should be considered to further understand how social connections influence health behaviors (Berkman & Glass, 2000). Research has suggested that in the development of health communication campaigns, interpersonal communication should be considered equally with other channels to disseminate health information (van den Putte, Yzer, Southwell, de Bruijn, & Willemsen, 2011). As an example, Ports et al. examined interpersonal communication as a channel for cervical cancer and HPV information in Malawi, recognizing the absence and limited of knowledge about cervical cancer screening and prevention. Participants from the study consistently commented that they would trust information through interpersonal communication channels such as doctors and nurses over all other channels for cervical



cancer information (Ports et al., 2015). Findings are likely to be common in other LMICs; however, consideration must be given to the reality of cervical cancer education via doctors in rural communities due to access and instead train community leaders or *promotoras* to deliver the information (Baezconde-Garbanati et al., 2014; Chen, Moran, Frank, Ball-Rokeach, & Murphy, 2018; Ports et al., 2015; Wilkin, 2013).

Various means of communication exist within communities, however, among rural and indigenous populations, interpersonal communication through daily encounters with other community members is the only viable means of communication (Luque, Tarasenko, et al., 2016). Understanding the role of “word of mouth” or interpersonal communication approaches to communicate health information has important implications for how women and men can learn more about the necessity of preventive screenings such as the Pap test. Understanding communication patterns of indigenous populations provides an opportunity to identify key informants to diffuse information to promote the use of cervical cancer screening opportunities (Wilkin & Ball-Rokeach, 2006). One operational explanation for this transfer of information is Valente’s discussion of the two-step flow hypothesis, which explains how some people pay attention to health messages through mass media or other channels, and then pass this information on throughout their social circles who have not directly been exposed to the mass media mechanisms (Valente, 1996). The two-step flow hypothesis is particularly useful in rural communities that may have limited access to mass media channels (e.g., TV, radio, website) and must rely on lay persons educated through interpersonal or other communication channels within the community.

In keeping with the community health worker model of disseminating information, one study demonstrated that women participating in a *promotora*-led randomized control intervention had significant increases in Pap test screening rates as well as increased knowledge and self-efficacy about cervical cancer (O'Brien et al 2010). Other studies have documented the benefit of women having a conversation about cervical cancer, asking questions, and gaining understanding through direct communication with a person over other mass media channels (Chen et al., 2018; Paz-Soldán, Nussbaum, Bayer, & Cabrera, 2010; Ports et al., 2015, p. 201; Torres, Erwin, Trevino, & Jandorf, 2013). The utilization of *promotoras* as an interpersonal communication channel can be influential in dispelling myths and misconceptions about the Pap test and cervical and used to inspire behavior change in a positive direction.

The purpose of this study was formative in nature, to identify preferences for health communication channels among women and men in urban and rural communities of Cusco, Peru that provided credible information and knowledge about cervical cancer screening.

## **METHODS**

### *Study sample and recruitment*

As part of a larger qualitative study examining the role of culture and gender dynamics, participants were recruited in June-July 2018 in urban and rural areas of Cusco, Peru. Patients attending health clinics offering access to cervical cancer screening to surrounding communities were included in the sample. Female and male participants were recruited in the health clinics. Women were invited to participate in the study after

receiving a Pap test. Males who were attending an appointment with a female partner or family member were invited as well. Female and male participants not seeking services through a clinic were also eligible to participate and were recruited from various community areas. Clinicians providing services in the health care clinics participated in the study at a time that did not conflict with patient care.

Urban and rural communities surrounding Cusco hosted health care clinics. The study participants were recruited to identify differences in knowledge about HPV and cervical cancer as well as to account for resources that may or may not be available communication channels within communities. Eligible females and males were between 25 and 60 years of age or had a partner or family member age-eligible to receive a Pap test per the recommendation of the Peruvian Ministry of Health which is a sector of the Peruvian government responsible for the access and availability of healthcare to Peruvian citizens (Alcalde-Rabanal, Lazo-González, & Nigenda, 2011). If a woman was outside of the 25 to 60 years of age range or was not willing to be interviewed independent of her partner, neither individual was invited to participate in the study.

#### *Data collection*

One-on-one semi-structured interviews were conducted with interview guides developed by the author based on existing literature (Oetzel et al., 2007; Paz-Soldán et al., 2010). Prior to the interviews, the guides were pilot tested in Spanish and Quechua with participants who met the study eligibility criteria to ensure the appropriateness and understanding of questions and terminology. Specific questions were asked about HPV, Pap tests, and cervical cancer knowledge; participants' preferences to receive more

information about HPV, Pap tests, and cervical cancer; if female, channels for information that would encourage them to get screened for cervical cancer.

Interviews were conducted with 20 females, 13 males, and six clinicians until saturation was reached (i.e. until no new information was found within each of the participant groups) (Creswell, 1998; Strauss & Corbin, 1990). Informed was obtained prior to the start of the interview. The interviewer explained the project in either Spanish or Quechua and signatures were obtained on an informed consent form acknowledging willingness to participate. Each interview lasted an average of 40 minutes, and S./20 Peruvian soles \$7 USD (2018 conversion was provided as appreciation for their time and effort. Institutional Review Board approval was obtained by both the University of South Carolina and the PRISMA Peruvian Institutional Review Boards prior to beginning any study activities.

### *Data Analysis*

De-identified transcripts were transcribed verbatim in Spanish and translated into English. In the case where the interview was conducted in Quechua transcriptions were reviewed by a native Quechua and Andean Spanish speaker for accuracy before translating into English. Transcripts were then cross checked against the audio files by two members of the research team for accuracy and proper contextual translations. To determine the coding scheme, English versions of the female, male, and clinician transcripts were hand coded by two independent reviewers and differences in coding were resolved to determine the first cycle codes that were conducted using NVivo® 11 Plus (QSR, 2010). A thematic analysis (Miles, Huberman, & Saldaña, 2014) was

conducted during a second cycle from the first cycle codes by synthesizing and collating smaller themes. These themes were reviewed a second time and coded again into broader categories. Themes were then stratified via matrix coding in NVivo by urban and rural categories. Upon completion of the thematic analysis, four themes emerged related to how participants preferred to receive information about cervical cancer.

## **RESULTS**

The total number of participants was 39, including 20 females, 13 males, and six clinicians. Demographic characteristics of the female and male participants can be found in Table 4.3. Clinicians were primarily based in urban areas of Cusco but also served women in rural communities ( $n = 5$ ), and one clinician worked in a rural health clinic. Three clinicians were *obstetricas* or nurse midwives, two were nurses, and one was a health education specialist. All had worked at their clinics for an average of 3.5 years.

Analysis and interpretation yielded four categories of themes: knowledge of HPV, the Pap test, and cervical cancer; preference for communication channel; interpersonal communication; and preferred message content. Additional quotes related to each these themes can be found in Table 4.4.

### **Knowledge about HPV, the Pap test, and cervical cancer**

Among female and male participants, knowledge about HPV, Pap tests, and cervical cancer varied greatly. Urban female participants were somewhat familiar with HPV, Pap tests, and cervical cancer and made connections about Pap tests can prevent cervical cancer. Approximately three participants exhibited understanding that HPV is the primary cause of cervical cancer. In the rural areas, much less was known about HPV, the purpose of Pap tests, and Pap tests connection to cervical cancer screening. While

many rural-dwelling women had heard of or even received a Pap test, they were not entirely clear on the purpose of the exam as a preventive screening test. Even less was known about HPV as the cause of cervical cancer among rural women. Male participants knew cervical cancer was a disease affecting women and Pap tests were something women received on a regular basis. Very few male participants (urban and rural) knew anything about HPV.

### **Preference for communication channels**

#### *Radio*

More participants in rural communities believed radio was a good method for communicating information about HPV and cervical cancer because many people listened to the radio and it was a viable channel to convey information to a large group of people. One rural female participant suggested, “Maybe in the radios. Aha. In the radios, news. Like that, so, since we’re here, listening to *huaynos*<sup>2\*</sup>, then we would hear it, there would be a little reflection.” A rural male participant also commented, “through the radio – to arrive to the communities – so to try to inform, no? Aha, through the radio.” A rural clinician also said, “The radio is also a good means in the mornings, no? Early in the morning, since they also wake up around 5 in the morning, then, they could listen to the radio.” Contrarily, one urban female participant shared her perspective on why the radio is not as reliable and stated, “—on the radio, from, uh, other people, they’re not going to tell me 100% right because we always—we don’t know. I for example, from what I know

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\* *huayños*: popular Andean music, folklore and dance

more or less, I'm going to explain it but, not like a doctor since they, uh, study, they know about that."

### *Television and video*

Television and videos were mentioned when participants were asked about their preferred channel for receiving health information but more so among clinicians and urban participants. One urban clinician mentioned, "Well, people watch television a lot. So, an advertisement would be good – on television and on schedules that, that they're together watching the T.V., no? Like mostly in the afternoon, at night. They watch. It would be better, no?, since they watch other programs that are not educational." Another clinician suggested, "The information should be sent – maybe through television media in advertisements. In the soccer advertisements for the men. Or of the women when they're watching a series, a telenovela." Despite these suggestions from clinicians, one urban male shared his perspective on why he thought television was not a good idea: "Information, it would be through the news. But here in Peru, they're not so truthful, no?"

A few women, mostly rural, mentioned wanting information in the form of a video. One woman said this about wanting video communication, "It could be videos. Nothing complicated. The simplest things. Because the truth is—I-I don't give myself time. And, I honestly, I'm very practical and whatever I don't understand, I throw it out." A rural female patient and community leader shared her ideas for wanting and getting information out in her community:

“Hmm, yeah. More trainings, or through videos. For example, I would join together the mothers for it, no? I would bring it for the mothers here some evening. So, I’d have them, mm, see a video. For example, at home, some of them hu—have a T.V., some don’t, so then they can’t watch it, no?”

### *Posters and written materials*

Posters and written materials were mentioned but to a lesser degree than other communication channels. Women, mostly in urban areas, wanted something written to read so they could refer back to it if they needed or to help them remember the information. One urban male suggested written information “through catalogues or magazines, and maybe through the media, since we’re most constantly with that.” One woman in a rural health clinic pointed to a poster on the wall and said “in brochures and on the poster boards like so. It has to be visual.”

### *Internet and social media*

Like posters and other written information, social media was mentioned only by urban male participants. When asked about what source he would like to receive information about HPV, one young man responded, “the internet. I used to have to Google since everybody knows English. And something else I really like I believe is the—the German sites.” Another urban male said “now that they exist, I believe that social networking, would be important.” This sentiment was confirmed by two clinicians that also mentioned social media as an option to disseminate information about HPV and cervical cancer, particularly for younger audiences saying “I think it [information] should be, uh, for the young population, through social media.



### *Multiple forms*

When participants were asked about how they would like to receive more information about HPV, Pap tests, and cervical cancer, a majority of the participants, females, males, and clinicians reported multiple channels as options for health communication messages on HPV, Pap tests, and cervical cancer. A number of participants but specifically females and clinicians mentioned that they would like a variety of sources of information about HPV, the Pap test and cervical cancer. Some mentioned a combination of radio and T.V. or talking with a doctor in addition to a more visible media channel. One clinician that serves urban and rural women commented:

“Whatever means of information that helps us to publicize or to-to raise awareness about cancer— because, uh, not everybody listens to the radio, not everybody watches T.V., nor—conversation, I mean, try to publicize it through whatever means possible. If it were through all of them, even better, because that’s how we give it out to many more people.”

## **Interpersonal Communication**

### *Patient-provider communication*

Among all of the sources participants in the sample named, female and male participants overwhelmingly wanted information primarily from a clinician about cervical cancer. Participants wanted information from the doctor first because they believed that they are the most trusted source of information contrary to those that might deliver information through other channels like television or radio. Other reasons include wanting the ability to interact with a person and ask questions so that they could understand the information better especially in areas where education and health literacy was minimal. One woman said this about wanting to talk with a doctor:

“That’s more trustworthy. You find out 100% well. On the other hand, from the radio or from TV, or from brochures—ah, I, for example, I don’t have much-much studies so, in some words I don’t understand very much. So, since I don’t understand much, I can’t explain. But on the other hand, talking with a person like this, face to face then I understand.”

A number of men also mentioned primarily wanting information primarily from a clinician. One urban male mentioned the importance of having a specialist to get information about HPV stating, “I would prefer a-a doctor more, but-but they have to have that specialty [gynecology] Because a lot of doctors—without having a specialty, they get involved in each area, right, of medicine. I would prefer that it’s a doctor with the specialty in that—in gynecology.”

#### *Workshops, trainings and other types of personal communication*

In keeping with the theme of interpersonal communication, a majority of rural female and male participants and some urban females were very interested in a workshop or training about HPV and cervical cancer. Participants valued being able to interact, ask questions and have more in-depth information about these topics because they thought it was the best means to increase their understanding. One female participant said:

“I would also prefer a professional, no?, who gives us talks, no? So, uh, I would ask, no?, or they would inform me. There’s always like a back-and-forth, no? They inform you, what it’s like. Mmm, you can prevent cancer. From that they talk to you sometimes, yeah the doctors, the doctors come from the health center. Like a training is given, no?” (Rural female)

### **Preferred message content**

When participants were asked about specific content they wanted to be included in the messaging, everyone wanted information that discussed the transmission of HPV, how to prevent it, how to treat it, and general knowledge about what HPV and cervical cancer is. Women wanted more information about what they could expect at the exam and clinicians suggested that more information is needed to educate women about what the Pap test is for and the connection between HPV, Pap tests, and cervical cancer. One clinician says:

“In reality, they have to know everything. What the infection is like, how the virus is acquired, how it develops and what causes it. Yeah? Uh, because the-the Human Papilloma Virus doesn’t only cause, 90% of cervical cancers but it also causes a percentage, of cancer of-of the anus, of the mouth, of the penis, of the throat. So they have to know all the information.”

### **DISCUSSION**

Findings from the study highlighted four categories of themes related to knowledge about HPV, the Pap test, and cervical cancer preference for communication channel; interpersonal communication; and preferred message content for information about cervical cancer.

Similar to other investigations of cervical cancer screening among women in Peru, the present study revealed generally low levels of knowledge about the Pap test, cervical cancer and its relation to HPV but particularly among rural residents of Cusco (Luque, Maupin, Ferris, & Condorhuaman, 2016; Paz Soldan et al., 2008; Paz-Soldán et al., 2010). In efforts to address the knowledge gaps recognized by participants, workshops, trainings and direct personal communication with doctors and informed friends and family were a popular resource requested by rural males in this study. This

finding is unique in that rural men took an active interest in wanting to know more about the topic. D’Orazio et al. mentions trainings of community health workers or *promotoras* as a popular method for educating women about cervical cancer but like many studies on this topic in Latin America, they only gathered perspectives from women (D’Orazio, Taylor-Ford, & Meyerowitz, 2014). This speaks to the desire of men to want more information about cervical cancer and to be informed for their female partners and family members despite men being reported to be *machistas* (Ulibarri, Raj, & Amaro, 2012).

Among all of the information channels mentioned, interpersonal communication with a doctor, specialist, or some professional expert on the topic was the most desired channel of information among female and male participants in urban and rural communities. Almost all of the men in the sample wanted information directly from a provider or an expert on the topic of cervical cancer. These findings are consistent with the study from Chen et al. that investigated patient provider communication and its positive impact on Pap test screening compliance (Chen et al., 2018). Participants often referenced having the most trust of information coming from experts compared to other people. However, having general conversations among peers and family members who knew about HPV and cervical cancer, was also mentioned often among participants. This finding is also consistent with previous research that suggests that women and men in Latinx communities can be valuable sources of information about cervical cancer particularly because of the patriarchal position on men and their role in healthcare decision making (Erwin et al., 2007; Paz-Soldán et al., 2010). Provided that the men we talked to showed genuine interest in wanting to be more educated about HPV and cervical cancer, indicates that an intervention involving men in the conversation of

cervical cancer may be a viable option to educate others, particularly other men, to normalize and promote Pap test screening and follow-up treatment where necessary. Additionally, interpersonal communication can improve social norms and conversations about cervical cancer (Allen et al., 2014; D’Orazio et al., 2014).

Not surprisingly, social media and internet was only mentioned by urban participants and a desired information channel about the Pap test and cervical cancer. This is most likely because internet access is unavailable in rural communities and the devices for which to access the internet are also not available. As previously mentioned, communication with healthcare providers and close friends and family, was the most desired method of communication in rural communities. TV and radio have been mentioned in other studies more specifically in the form of telenovelas and celebrities and were likewise suggested by clinicians in this study (D’Orazio et al., 2014). Videos were mentioned a few times among rural female participants as a channel for information about HPV, the Pap test and, cervical cancer. This finding is consistent with studies that have shown videos to be a viable option for communicating information about Pap and colposcopy among indigenous populations (Ferris, 2009; Ferris et al., 2015). Posters and written materials were only mentioned among urban female participants which calls for attention to the education literacy levels that factor into desired communication channels. As an example, Best and colleagues provide recommendations for the use of a health literacy framework in communicating information about HPV and cancer as a means to tailor appropriate messages to different audiences (Best et al., 2018).

The study does have some limitations. While the use of qualitative methods provided in-depth information, findings cannot be generalized to larger or other

populations. Additionally, while participants reported their personal preferences for wanting more information about HPV, Pap tests, and cervical cancer, studies such as this could benefit from quantitative and intervention studies that measure the impact of desired communication channels on actual Pap test screening uptake. Despite these limitations, this study had several strengths. The open-ended nature of the questions asked of participants gave way to the etic perspective without any suggestive input from researchers. Additionally, having a variety of perspectives from females and males in both urban and rural communities as well as clinicians provides additional insight into what types of channels are useful in the development of communication interventions in a varying of Latinx audiences.

## CONCLUSION

Communication with doctors was the most desirable mode of communication requested by participants, however, the reality of clinicians' availability for one-on-one communication may be limited. The use of community health workers (*promotoras*) is one method to disseminate trusted information from healthcare providers into communities where access to a health center is a barrier. *Promotoras* are also helpful in dispelling myths and misconceptions about the Pap test and provide credible and accurate knowledge to community members that have minimal communication resources. Likewise, it is important to consider a variety of health literacy needs and community contexts and make sure resources are congruent with what is available to deliver effective health communication messages. Finally, engaging government and policy stakeholders for insight and buy in on message delivery could add to the credibility of information and presence in communities. It is anticipated that formative studies such as this will

contribute to the larger body of health communication literature on cervical cancer prevention and control for the development of effective and culturally tailored communication practices specifically designed for screening uptake and follow-up care.

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**Table 4.3 Demographics of research participants\***

	<b>Female (n = 20)</b>	<b>Male (n = 13)</b>	<b>Total (n = 33)</b>
	Frequency (%)	Frequency (%)	Frequency (%)
<b>Participant age (mean)</b>	42	36	24 - 58
<b>Marital status</b>			
Married	16 (80)	6 (46)	22 (67)
Single/ Cohabitants	3 (15)	7 (54)	10 (30)
Widowed	1 (5)	0 (0)	1 (3)
<b>Residential location</b>			
Urban	5 (25)	4 (31)	9 (27)
Rural	15 (75)	9 (69)	24 (73)
<b>Highest education</b>			
Elementary school (Primary)	11(55)	0 (0)	11 (33)
Middle + high school (Secondary)	5 (25)	5 (25)	10 (30)
Technical school (Vocational)	0 (0)	3 (23)	3 (9)
College (Tertiary)	4 (20)	4 (31)	8 (24)
<b>Employment status</b>			
Full-time	10 (50)	8 (62)	18 (55)
Part-time	0 (0)	3 (23)	3 (9)
Homemaker	8 (40)	0 (0)	8 (24)
Unemployed/student	2 (10)	2 (15)	4 (12)
*excludes demographics of clinicians			

**Table 4.4 Participant quotes by theme and urban and rural residence**

Theme	Urban	Rural
<b>Knowledge about HPV, the Pap test, and cervical cancer</b>	“I don’t know what —how it happens, but it appears at an older age, an older person, I believe past twenty-five or more is an age, that it happens to women.” (male)	<p>“A Pap exam I think they get it done once a year, no? Or every three months, or six months per year for women. For breast cancer.” (male)</p> <p>“No, sometimes it’s born from being dirty mm or it’s in other women, right? Their partners. So it’s raised from those things. And in the heat, right, uh, they walk to the fields with pants, from those things. And then they don’t change their underwear. Ah, or they wear the same thing for the week, no? And from those things, the STIs advance until they become that, that thingamajig, it passes into cervical cancer, right, Ma’am?” (female)</p>
<b>Preference for communication channel</b>		
Radio	<p>“Mm, maybe the radio but the thing is that the youth don’t listen to the radio or, uhm, a news bulleting, they go more to music. (clinician)</p> <p>“And the radio is very tuned-in to so that would help a lot with communication.” (clinician)</p>	<p>Eh, I like to hear more from the radio (female)</p> <p>Mmm, through the radio would also be good. (male)</p> <p>Mm, of course, like so, quickly, through the radio, no? (male)</p>
T.V or video	So I would like it be seen on TV, for example, no?, the consequences that this disease brings. And also...or like, what this disease carries, all those, uh, that-that illness then so to be able to avoid it because a lot of us are blind, and we commit errors.” (female)	<p>It could also be through the T.V. --and on the poster-boards too. It has to be visual. (female)</p> <p>What would help the most might be something on T.V or the radio. Aha. T.V. more than anything, yeah. (female)</p>



	It could be videos. Nothing complicated. The simplest things. (female)	
Trainings and workshops	So, they're more interested in the demonstrations. In their own language, without using medical terminology. With materials, their own language. Something that helps a lot, is the – charisma. Capture their attention, talking isn't enough. (clinician)	<p>I would like more for them to give us talks (female)</p> <p>It would have to be in some training (session) miss. Even having a training (session) from, from the doctors, at least from you guys, maybe you all know more about all those things, no? (male)</p> <p>Maybe, training a leader, like so, leaders. (male)</p>
Posters or written materials	<p>Through a flyer would be better...to read it. (female)</p> <p>The truth is I love infographics. (female)</p> <p>I would forget about these—hmm, these words, the flyers would help me remember. (female)</p>	Yeah in brochures--and on the poster-boards. It has to be visual. (female)
Internet and social media	<p>The internet, I used to have to Google but since everybody knows English. And something else I really like I believe is the—the German sites.(male)</p> <p>Now that they exist, I believe that social networking, would be important. (male)</p> <p>And I also think that the topic of WhatsApp, of WhatsApp I think that now we already have cell</p>	

	<p>phones that have connected us so-so much, right? (male)</p> <p>The information should be sent through social media. (clinician)</p>	
<b>Interpersonal Communication</b>		
Patient-provider communication	<p>I think someone from the specialty, no? A gynecologist, but they need to tell you the things as they really are, no? (female)</p> <p>So, people are not well informed of all of that, right? So, who are the ones called to give us the right information, scientific information? Medical professionals are the ones called. (female)</p> <p>From the doctor would be good—Because the doctor sees more of these things, so the doctor would explain it better. About-about what things prevent those diseases, things like that, friend. And I would like to hear more about that cancer, to hear more about it. (urban female)</p> <p>I believe—I would prefer a-a doctor more, but-but that they have that specialty Because a lot of</p>	<p>I would also like it from the doctor. Since they inform us more, clearly, details, and also to ask them [questions]. (female)</p> <p>Personal (communication) would be better. Of course, a (female) doctor. To the (female) doctor I can, yeah to ask, “How—explain this to me,” like so. (female)</p> <p>Mm, I think he informs me—the doctor would inform me more about, no, about cervical cancer. (female)</p> <p>“I would also prefer a professional, no?, who gives us talks, no? So, uh, I would ask, no?, or they would inform me. There’s always like a back-and-forth, no? They inform you, what it’s like. Mmm, you can prevent cancer. From that they talk to you sometimes, yeah the doctors, the doctors come from the health center. Like a</p>

	doctors that—without having a specialty, they get involved in each—in each area, right, of medicine. I would prefer that it's a doctor with the specialty in that—in gynecology. (male)	training is given, no?" (female)
Trainings workshops and other personal communication	<p>So, they're more interested in the demonstrations. In their own language, without using medical terminology. With materials, their own language. Something that helps a lot, is the – charisma. Capture their attention, talking isn't enough. (clinician)</p> <p>Hmm, we don't talk about in in the community, but I would like to receive a... a... workshop, right? About cancer so we can prevent from that cancer. Because I...in my community there are many mothers that-that don't know about it, and...I would like something like that...a workshop. Coming to my community to have them get a Papanicolaou, like that. (female)</p> <p>I would tell you guys for one thing, I would be so grateful to you guys if, to all of the ladies, if really, for example we work in the market, we don't have that support. No? Sometimes the very government thinks about the great people and the people from the countryside, but the middle-class people that we are, we're the ones that work the most, the ones that receive support the least, for example there should be a talk, an orientation, for example for the</p>	<p>"I would like for them to do some workshops, right? Some campaigns." (female)</p> <p>"I mean I would like, maybe, for my friend to know more, yeah?, about that cancer, no?, so I would like them to inform me more, so I know. Aha, like that, only among ourselves." (female)</p> <p>Through personal (communication) and...with my female friends. (female)</p> <p>We spread the word among ourselves. (female)</p> <p>I mean, to receive it would serve us a lot in order to prevent like so. So, honestly, I would beg you guys maybe in some way how we could – uh, maybe I, personally, or somebody else, you guys could come to prepare us in that, so then to report back in the communities, no? Because one person when s/he is in that, with that disease, then s/he already feels uncomfortable, anxious, like, s/he's no longer con—normal, no? So, it would be for me extremely important. (male)</p> <p>That would be, like this, ah, in person like this with, mm, a friend. Or, mm, yeah, no?, talking about that</p>

	middle-class people, which is us. There should be that type of, uh, orientations, explanations, and those talks that we should receive. (female)	topic would be—I would love it. (male)
		<p>“I would like to receive a workshop, maybe, with models, right? that show you the parts, the parts of our-our genitals. To tell us, ‘this is that. This and that’, right? How to do—to do the—the hygiene, all that, right? Because many times, a lot of women, we don’t know how to do our own hygiene correctly. That’s very important too. Right? So, I would want that. To start maybe from the reproductive system, all that. To not only make women aware but also the men. Together, right? (female)</p> <p>It would have to be in some training (session) miss. Even having a training (session) from, from the doctors, at least from you guys, maybe you all know more about all those things, no? (male)</p> <p>Maybe, training a leader, like so, leaders. (male)</p>
<b>Preferred message content</b>	<p>What the consequences of HPV are, how HPV is spread. Explain to them that there’s no initial treatment or like nor do they know how it--, how it’s [HPV] spread. They need to know it’s spread by sexual intercourse. (clinician)</p> <p>I believe they need greater broadcasting and greater—mm, they have to explain it to them better. Because there are many people who still don’t even know what the Pap exam is, or what it is we’re going to-to prevent with the Pap exam. (clinician)</p>	

	<p>Uh... that they make us know exactly what is cervical cancer. If we don't know what it is, we can't do anything either. Nor perhaps request information over that disease. (male)</p> <p>I mean with respect to protecting oneself from cervical cancer uh I believe that the HPV vaccine would be better, right, because each person then receives three doses to protect oneself from HPV and if the young people for example yeah they can protect themselves, they're not going to contract it, no? Yeah it's of course, if—if they sell it here, in the pharmacies because as they are small campaigns, just a group of only women, of girls, no?, and adolescents in that group also, and the rest [males] are left to their own—just to chance. (male)</p>	
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## CHAPTER 5

### DISCUSSION

The final chapter of the dissertation will recap the findings for each aim of the study and a discussion of the findings from the research overall. The chapter will subsequently provide a conclusion of the findings and discuss the strengths and limitation of the research. The chapter will conclude with a section each on the implications for public health practice and future directions for how the dissertation work could move forward.

#### **Summary of findings**

The goal of this dissertation research was to explore sociocultural influences on cervical cancer prevention and control behaviors among communities throughout Cusco, Peru through two specific aims, 1) to explore the influences of cultural beliefs, stigma, and *marianismo-machismo* gender ideologies on cervical cancer prevention and control behaviors among women and men in urban and rural areas of Cusco, Peru and 2) to identify preferences for health communication channels to increase cervical cancer prevention and control behaviors among women and men in Cusco, Peru. The first aim of the study explored cultural beliefs and the influence of gender dynamics on cervical cancer prevention and control, but more specifically the Pap test. Aim 1 was guided by

the cultural identity, cultural empowerment, and relationships and expectations domains of the PEN-3 theoretical framework. Findings suggested that the primary cultural influences on cervical cancer screening can be tied back to cultural empowerment and the positive, existential, and negative perceptions of the Pap test and cervical cancer when the relationships and expectations of community members nurture, enable, or perpetuate these perceptions.

This study was unique in that it included men into the overall conversation about cervical cancer. A male perspective is important to understanding the cultural context of the area because men contribute to the established cultural norms about cervical cancer prevention and control, and cervical cancer is caused by a sexually transmitted infection (HPV) transmitted through sexual relations with men. Additionally, men are the patriarchal heads of the household, particularly in Latin American countries, and play a role in the healthcare of women (Nuñez et al., 2016). One salient finding was that female and male participants believed that the Pap test itself causes cervical cancer and is one reason women have not gotten screened. Other issues related to fear included fear of the exam, fear of the husband, fear of male doctors, and to a lesser degree – fear of the results. Most of these findings related to fear are consistent with those of previous studies in the Peruvian region (Liebermann et al., 2018; Luque, Maupin, et al., 2016; Paz-Soldán et al., 2010). Limited knowledge about the connection between HPV, the Pap test, and cervical cancer, not fully understanding the purpose of a Pap test, beliefs that the Pap test was going to be a painful or traumatic experience, and fear and embarrassment with exposing their bodies during the exam, were also consistent with findings of previous

studies conducted in other parts of Peru. (Luque, Maupin, et al., 2016; Paz-Soldán et al., 2010).

Urban and rural comparisons were made to understand cultural similarities and differences between these populations and responses generally varied based on urban and rural residence. Urban participants were more knowledgeable about the Pap test and causes of cervical cancer, were less afraid of the Pap test, and had more positive conversations about the topic compared to rural participants. Education level was also related to cultural beliefs about the causes of cervical cancer and the purpose of a Pap test. Individuals with higher levels of education were more knowledgeable about cervical cancer and its causes compared to those with less education, which also differed between urban and rural residents. Most misconceptions, feelings of embarrassment, fear, and negative community conversations about the Pap test and cervical cancer existed among rural dwelling women and men.

During the course of conducting interviews, one participant mentioned former President Alberto Fujimori who was in office from 1990-2000. The comment was raised in connection with community conversations about the Pap test and cervical cancer. Between 1996 and 2000, former President Alberto Fujimori instituted the National Reproductive Health and Family Planning Program, by which over 200,000 mass sterilizations of rural women and men occurred throughout the Cusco province (Collins, 2014; Intercontinental.Cry, 2016; Lizarzaburu, 2015). Some areas where these sterilizations took place included districts of the participants in the sample (“REVIESFO Register of Victims of Forced Sterilization,” 2017). During the interviews, female participants spoke about conversations they have had in their communities about the Pap



test and made references to being afraid or knowing women who were afraid because they thought something was going to be taken from them, or they would be harmed in some way. This was the case when women were sterilized, many of them unknowingly, during the time of Fujimori. That mass sterilizations happened within the same communities for this study, might explain some of the references to fear and misconceptions associated with receiving a Pap test.

Inquiry into men's knowledge about HPV, the Pap test, and cervical cancer was a means to explore sociocultural beliefs about these topics from both female and male perspectives. Conversations about the Pap test and cervical cancer require communication between women and men about sexual transmission of HPV and the component of a women needing to undress in front of a male clinician for the Pap test screening process. In the context of Latin American culture, conversations about sex and undressing in front of a male clinician can be influenced by the *machismo-marianismo* gender dichotomy which consequently might impact women's decision-making for screening, regardless of the woman's knowledge about the Pap test and cervical cancer (Moreno, 2007; J. B. Torres et al., 2002). Results from the investigation of gender dynamics between women and men in Cusco, Peru about cervical cancer screening uptake uncovered six primary themes including men's knowledge of the Pap test or cervical cancer, men's attitudes toward the Pap test, gender preferences for administration of the exam, *machismo*, *marianismo*, and spousal support.

Despite the self-reported lack of knowledge about the Pap test and cervical cancer, men recognized the topic of cervical cancer as important and wanted more information for themselves and to take back to their communities. Clinicians

acknowledged the impact of *machismo* on women's Pap test uptake due primarily to the absence of information about Pap tests and cervical cancer and likewise mentioned that, as men become better educated on the topic, they are see more spousal support and women feeling empowered to get a Pap test. Regarding perspectives of men's attitudes toward the Pap test and cervical cancer, most female participants in urban and rural areas perceived men as having a negative or dismissive attitude, whereas men in urban, and even some rural areas, were supportive of women getting a regular Pap test. The difference in perspectives among females and males about the Pap test and cervical cancer were also similar in the findings of spousal support for Pap tests, although reports of the lack of spousal support occurred primarily among women in rural areas. Comments from clinician participants also confirmed these differences in gender and residential perspectives based on their interactions and locations of the patients they served.

Similarities between female and male participants were such that most preferred gender concordance, in this case a female clinician, to administer the exam since women were purportedly afraid of men and men did not want other men touching their women. This finding is consistent with other studies among women in Central and South American communities where women were afraid to be seen by a male physician due to controlling or abusive spouses (Erwin et al., 2010; Luque, Maupin, et al., 2016). However, there were several instances where male participants referred to the idea that something traumatic or dangerous might happen with a male clinician, such as abuse or damage to a woman's body. Direct accounts of male preferences for a female clinician may have been for protective reasons and not necessarily always associated with negative *machista* behaviors.

Regarding specific *machismo* influences, all participants drew distinct differences between urban and rural areas where *machismo* had a direct impact on the decision-making of women to get a Pap test. Clinician and female participants referenced some women as silent in the presence of men, submissive, and in situations of physical and sexual abuse from their husbands. These findings closely aligned with the quantitative predictions from Arredondo et al. in which there was a lack of cervical cancer screening among women who experienced *machismo* compared to those who screen regularly (Arredondo et al., 2008). It is important to note that in the rural areas, there was substantial overlap between the themes of *machismo* and men's attitudes (negative), gender concordance for the Pap test exam, *marianismo*, and lack of spousal support. Collectively, these findings contribute to research suggesting the need to examine gender roles and sexual beliefs as they relate to cervical cancer (D'Orazio et al., 2014).

Examining the *machismo-marianismo* gender ideologies in Cusco, Peru provided insight into the sexual dynamics, particularly in rural areas, that have a direct effect on the healthcare of women in these communities; and where cervical cancer-related interventions should be targeted. While *machismo* does exist in various communities, it cannot be generalized to all men in South America or Peru. This study identified men in urban and rural areas that are supportive of women's health and would be inclined to be more included with increased knowledge about topic of cervical cancer. An important facilitator of increased spousal support would be the inclusion of men in cervical cancer screening educational interventions and honoring the patriarchal head and influence on healthcare decision making among women throughout this region.

The second aim of the study, to identify preferences for health communication channels to increase cervical cancer prevention and control behaviors among women and men in Cusco, Peru, examined the health communication channels and preferences of Cuscaininan women and men and the integral role of interpersonal communication as a means to disseminate knowledge about HPV, the Pap test, and cervical cancer. Findings from this aim highlighted four overall categories of themes related to communication about HPV, Pap tests, and cervical cancer. Knowledge about HPV, Pap tests, and cervical cancer; preference for health communication channels; interpersonal communication; and preferred message content about cervical cancer were the most prominent themes for this portion of the study.

Similar to other investigations of cervical cancer screening among women in Peru, the dissertation research revealed generally low levels of knowledge about HPV, the Pap test, and cervical cancer and its relation to HPV. Limited knowledge was particularly low among rural residents of Cusco. In efforts to address the knowledge gaps recognized by female and male rural participants, workshops, trainings, and direct personal communication were mentioned most for health information. This finding is unique in that rural men took an active interest in wanting to know more about the topic. D’Orazio et al. mention training community health workers or *promotoras* as a popular method for educating women about cervical cancer, but like many studies on the topic of cervical cancer in Latin America, they only gathered perspectives from women (D’Orazio et al., 2014). This speaks to the desire of men to wanting more information about cervical cancer and to be informed for their female partners and family members despite men being reported to be *machistas* (Ulibarri et al., 2012).

Among all of the health communication channels mentioned, interpersonal communication with a doctor, specialist, or professional on the topic was the most desired channel for information among female and male participants in urban and rural communities. Almost all of the men in the sample wanted information directly from a provider or an expert on the topic of cervical cancer. These findings are consistent with the study from Chen et al. that investigated patient provider communication and its positive impact on Pap test screening compliance (Chen, Moran, Frank, Ball-Rokeach, & Murphy, 2018). Participants often trusted information from experts the most. However, having general conversations with peers and family members who knew about HPV, Pap tests, and cervical cancer, was frequently mentioned among participants. Trusting peers and family members for health information is also consistent with previous research that suggests that lay women and men in communities can be valuable sources of information about cervical cancer. Educating men about the importance of HPV, the Pap test, and cervical cancer is particularly important because of their role in healthcare decision making (Erwin et al., 2007; Paz-Soldán et al., 2010). Provided that the men we talked to showed genuine interest in wanting to be more educated about HPV, Pap tests, and cervical cancer, indicated that a cervical cancer intervention involving men may be a viable option to educate others, particularly other men, to normalize and promote Pap test screening and follow-up treatment where necessary. Additionally, interpersonal communication through this avenue can improve social norms and conversations about cervical cancer (Allen et al., 2014; D’Orazio et al., 2014).

As expected, social media and internet resources were only mentioned by urban participants and a desired channel for health communication about the Pap test and

cervical cancer. This is most likely because internet access is unavailable in rural communities and the devices for which to access the internet are also not available. As previously noted, interpersonal communication with healthcare providers and close friends and family, was the most desired method of communication in rural communities. TV and radio have been mentioned in other studies, more specifically, in the form of telenovelas and celebrities and were likewise suggested by clinicians in this study but not participants (D'Orazio et al., 2014). Videos were mentioned a few times by rural female participants as a channel for information about HPV, the Pap test, and cervical cancer. This finding is consistent with studies that have shown videos to be a viable option for communicating information about Pap and colposcopy among indigenous populations (Ferris, 2009; Ferris, Condorhuaman, et al., 2015). Posters and written materials were only mentioned by urban female participants which calls for attention to the education literacy levels that factor into desired communication channels. As an example, Best and colleagues provided recommendations for the use of a health literacy framework in communicating information about HPV and cancer as a means to tailor appropriate messages to different audiences (Best et al., 2018). As such, it is important to consider a variety of health literacy needs and community contexts, and to make sure resources are congruent with what is available to deliver effective health communication messages.

## **Conclusions**

Knowledge about the relationship between HPV, the Pap test, and cervical cancer remains low in communities throughout Cusco, Peru. In order for cervical cancer knowledge to increase, sustainable community-led education efforts will be needed, particularly in rural areas. While there are significant knowledge gaps in rural areas

perpetuated by a number of misconceptions, women and men in urban communities can also benefit from increased knowledge in this area. As knowledge increases throughout a community, ideally community empowerment would also increase alongside regular cervical cancer screening practices. One important element is the incorporation of men into cervical cancer education interventions. Education and buy in from men in the community is essential to increasing screening behaviors. As women are empowered to get screened with the support of their husbands, collective interventions that address geographical, structural, and capacity barriers to screening, will ultimately decrease the mortality of cervical cancer throughout the region.

Coding emergent themes in this study based on the PEN-3 theoretical constructs of cultural identity, cultural empowerment, and relationships and expectations, was a means to situate the topic of cervical cancer in Latinx culture and elucidate specific areas on which interventions to increase knowledge and screening practices should focus. As an example, health communication interventions within the Cusco region are wanted by women and men in Cusco. Findings from the formative work provided by the dissertation research can be used to illuminate participants perspectives about what they want and can be beneficial to the development cervical cancer education interventions.

Consideration must be given to sociocultural factors in the process of developing interventions to improve knowledge and to reduce structural barriers for cervical cancer screening. Provided that indigenous communities throughout Cusco experienced the historical horror of mass sterilizations, community and stakeholder buy-in is essential to rebuild trust in the medical system. Historical injustices are not easily erased and more studies in the areas of healthcare delivery should account for the impact of these

injustices on the attitudes, behaviors, and barriers to disease burden such a cervical cancer. Sociocultural influences on screening behaviors can be changed – slowly when proper intervention programs incorporate communities and use their communication preferences to develop and disseminate information.

### **Study Limitations**

This study had some limitations that are worthy of discussion. First, there were no male clinicians included in our sample. No male clinicians provided Pap tests during the time of data collection for this study. A male clinician perspective would have enriched our findings about the gender preference for the Pap test would have further triangulated reports from the female and male participants. Second, it was difficult at times to recruit males in urban and rural communities to discuss a health topic that affects women.

Taking into account that two female researchers led the study, the gender of the researchers could reflect prevailing norms related to gender concordance concerning a woman-centric issue. While we are unsure of the degree to which this was the case, other factors that may have contributed to recruiting males, such as communication barriers or work day interference. To alleviate these barriers, a fully implemented community-engaged approach involving partnerships with male and female community members or health promoters (*promotores*) to conduct the interviews could alleviate participants' discomfort due to gender and nationality differences. This approach could also extract deeper issues in the community that participants are not comfortable sharing with foreign researchers. Third, men may not have understood the full process involved with a Pap test. This may have resulted in some men responding to information that they knew only superficially about a Pap test without having full knowledge of the procedure. Fourth,



more female participants than expected reported having a Pap test. While conceptually this could be viewed as a positive outcome, it is possible that social desirability to report an up-to-date screening status may have occurred particularly in rural areas as participants may have felt compelled to participate due to the financial compensation for their involvement. It is important to note that while participants reported having a Pap test, many of their responses also reflected experiences with other women and men in their communities and how they view cervical cancer screening practices.

Qualitative research methodology lends itself to the *etic* perspective and researchers' world view approach to the topic under study. Despite the phenomenological approach to data analysis and interpretation, it is possible that the observer's perspective was not completely eliminated from the investigation. In qualitative research, the degree to which issues identified by participants directly impact cervical cancer screening uptake could not be measured directly. A final limitation to the qualitative approach was the language barrier between the lead researcher and the sample population. This resulted in having to rely heavily translation by a team member and a rigorous translation and verification process of transcripts for analysis. Since the decision was made to implement a rigorous verification process, there was limited time between interviews to do extensive data cleaning and analysis in between interviews. As one example, it was difficult to determine how many responses from women and men in the sample were influenced by the historical event of mass sterilizations experienced in the same communities where this study took place.

## Study strengths

Despite noted limitations, there were several notable strengths. First, researchers were able to access and interview a range of participants throughout the Cusco region, particularly in rural districts where most previous studies in Peru had not been extensively studied qualitatively. Second, the inclusion of men in all aspects of the study was unique in that a majority of the studies that have explored attitudes, barriers, and cultural aspects of cervical cancer only engaged the perspectives of women. Relationships with clinicians allowed us to collect information from them to triangulate data gathered from female and male participants thereby reducing researcher bias. Additionally, having clinician perspectives to triangulate what women and men reported about sociocultural influences within communities, *machismo*, *marianismo*, spousal support, and the attitudes of men related to the Pap test helped to provide a well-rounded perspective on the issues that were identified in urban and rural communities. Third, the research team included a native Peruvian speaker of Andean Spanish and a linguist that specializes in romance Andean languages which allowed for a rigorous transcription and translation process. Fourth, a native speaker of Quechua and Spanish was available to assist with verification of the monolingual Quechua interviews to strengthen validity of the conversations that were recorded in the indigenous language. Fifth, the use of a qualitative approach to explore the cultural impacts on cervical cancer screening behaviors was useful in providing an in-depth, individual perspectives on the topic of cervical cancer.

## **Implications for public health practice**

Findings suggested that sociocultural influences may to some degree impact cervical cancer screening uptake throughout the Cusco region. Regarding the cancer experience as a whole, disparities in cancer rates can be caused by the interplay of culture, socioeconomic class and poverty, but must also acknowledge the presence of historical social injustices (Freeman, 2004). Behavior change necessitates a culturally-sensitive education that acknowledges the historical disturbance caused by former President Alberto Fujimori and empowers the community to recognize the importance of women's health.

Cervical cancer and Pap tests might be considered taboo to some and remain undiscussed by others. However, most participants reported a willingness to talk with loved ones about HPV, the Pap test, and cervical cancer if they were more knowledgeable about the topic. Increasing the health education of community members in the Cusco region is essential to dispel misconceptions about Pap tests and cervical cancer particularly in rural areas. Acknowledging the role of men in sexual health interventions is also a means to address one of the sociocultural barriers to cervical cancer screening. Involving men, can create bi-directional education with male-female dyads and increase the likelihood of approval of screening and prevention of cervical cancer. Moreover, when men are involved in educational efforts, they can become a positive support system and resource for a reminder to maintain regular screening uptake.

Although interpersonal communication with doctors was the most desired channel of information requested from participants, the reality of clinicians' availability for this mechanism of communication is likely to be limited. To address this, the training

of community health advocates by physicians and nurses is a means to develop reliable sources to disseminate information into communities especially if access to a health center is a barrier.

### **Future Directions**

Findings can be used by researchers working to understand and intervene on cervical cancer disparities within LMICs to develop, adapt, or implement interventions that directly address sociocultural barriers to cervical cancer prevention and control. Researchers can also use quantitative methods to measure the degree to which the themes identified in this study, such as the *marianismo-machismo* gender ideologies, directly correlate or influence cervical cancer screening uptake within these communities. Participants reported their personal preferences for wanting more information about HPV, Pap tests, and cervical cancer. Health communication studies could also benefit from mixed method intervention studies to assess the impact of desired communication channels on actual Pap test screening uptake. It would also be essential to incorporate a health literacy framework and consider specific community contexts to make sure the delivery and content of messages are congruent with the availability of resources to deliver effective health communication messaging.

Continued studies on social network influences on cervical cancer screening practices would be particularly useful in developing approaches to increasing both knowledge and screening uptake in LMICs that are looking for resourceful ways to disseminate health information. Social network data were collected from female and male participants during the interview process. Due to the amount of data gathered, analysis for future studies will be performed at a later time. As determined by the dissertation

research, interpersonal communication is a valuable channel to spread information when individuals are properly informed and educated about cervical cancer. Finally, engaging government and policy stakeholders for insight and buy in on message delivery could add to the credibility of information and presence in communities.

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APPENDIX A  
INTERVIEW GUIDES

**Interview Guide and Social Network Questionnaire (ENGLISH)**

**(Female Participants)**

**Location:** \_\_\_\_\_ **Date:** \_\_\_\_\_ **Start time:** \_\_\_\_\_ **End time:** \_\_\_\_\_

**Interviewer Initials:** \_\_\_\_\_

**Introduction**

**Interviewer script:**

*Hello! Thank you again for agreeing to talk with me today. My name is Venice Haynes, and I am a student at the University of South Carolina in the United States of American. This is Bethany Bateman, and she is a student at the University of Georgia also in the United States. We will be working together during this interview to learn from you about the social relationships and your culture as it relates to what people know about human papillomavirus (called HPV) and cervical cancer. We also want to ask for any suggestions you might have for the types of information you would like to see to learn about HPV and cervical cancer.*

*Taking part in this interview is completely voluntary, so please know that you can stop at any time if you do not feel comfortable continuing the conversation. You also do not have to answer any questions you don't feel comfortable answering. The interview will last about 45 minutes. I will be recording the conversation so that I capture everything that you say in your own words. I will not write or use your name in association with anything that you share with me today. Your participation or lack of participation will not affect your clinical care.*

*Are you still willing to participate in the interview?*

Consent to participate \_\_\_\_\_ (yes/no)

*Do you have any questions before we begin?*

*Great! Let's get started...*

**{TURN ON RECORDER}**



### **Demographic Questions**

**1. What is your language preference?**

- ☐ Spanish How often? \_\_\_\_\_
- ☐ Quechua How often? \_\_\_\_\_
- ☐

**2. What is your age?**

Age \_\_\_\_\_

**3. Marital status?**

- ☐ Single
- ☐ Married
- ☐ Separated
- ☐ Widowed
- ☐ Divorced

**4. What is the highest level of education you have received?**

- ☐ No schooling
- ☐ Primary
- ☐ Secondary
- ☐ Undergraduate
- ☐ Graduate School
- ☐ Other

**5. Do you work?**

- ☐ Full-time
- ☐ Part-time
- ☐ Do not work
- ☐ Other

**6. Do you consider yourself and urban or rural resident?**

- ☐ Urban
- ☐ Rural
- ☐ Don't know

**7. Have you ever had a Pap test before?**

- ☐ Yes When \_\_\_\_\_? (years)
- ☐ No
- ☐ I don't know

*If at the participant is a patient at the clinic or at a Pap campaign, ask the following:*

**8. Are you here today because you are experiencing symptoms or for cervical cancer prevention?**

- ☐ Symptoms
- ☐ Prevention
- ☐ Don't know

*Thank you for this information. I will now begin with a few questions about what you know about HPV (human papillomavirus) and cervical cancer.*

## **Part 1. Knowledge about HPV and Cervical Cancer**

---

*First, I would like to ask you about what you have heard or what you know about HPV and cervical cancer. If you do not know an answer, it is ok to say you don't know.*

- 1. Please tell me what you have heard or what you know about HPV.**
- 2. Please tell me what you have heard or what you know about cervical cancer.**
- 3. What do you think are the causes of cervical cancer?**
- 4. Why do you think a Pap test is done?**

*If the woman does not know about HPV, cervical cancer, or the purpose of a Pap test, please read the following note about it:*

*HPV is very common and is passed from one person to another during sexual activity. It is so common that nearly all sexually active men and women get it at some point in their lives and most of the time it goes away on its own. When it doesn't go away in women, HPV can cause abnormal Pap tests and even cervical cancer. The Pap test (or Pap smear) looks for pre-cancers, which are cell changes on the cervix that might become cervical cancer if they are not treated. Cervical cancer is almost always caused by HPV. Vaccines are available to protect against the types of HPV that most often cause cervical cancer.*

*The Pap test is recommended for women between ages 25 and 65 and can be done in a doctor's office or clinic. If your Pap test results are normal, your doctor may say you can wait three years until your next Pap test. If your test results are normal, your chance of getting cervical cancer in the next few years is very low. Cervical cancer is highly preventable with regular Pap tests and follow-up care. It also can be cured when found early and treated.*

*{excerpt adapted from*

*<https://www.cdc.gov/cancer/dcpc/resources/features/cervicalcancer/index.htm>}*

*{ask the following questions if at the CerviCusco clinic or campaigns}*

5. How did you hear about the screening or vaccine services today?
6. What made you decide to get a Pap test today?
7. When did you last get a Pap test before today? (if answer to question 6 above is yes)  
*Probe: If you can remember, please tell me about your experience.*

*{ask everyone these questions}*

8. If you have had a Pap test before, how old were you when you got your first one?
9. What do you wish you had known about your visit that you did not know before going in?
10. If a doctor told you that you had abnormal results and needed to come back for follow-up care, what would make you come back?  
*Probe: what are some reasons that would make you not come back?*  
  
*What would you need to help you understand when to come back and why?*
11. Have you heard about the HPV vaccine?  
*Probe: Have you vaccinated your children? Why or why not?*

## **Part 2. Sociocultural influences**

---

*I would like to switch our discussion a bit to talk about the people in your life and how supportive they are of your health.*

1. Have you ever experienced feelings of embarrassment or shame getting a Pap test?  
*Probe: Please tell me more about those feelings.*  
  
*Probe: Did someone make you feel that way?*
2. How willing would you be to talk to others in your family or community about HPV and cervical cancer?  
*Probe: Why or why would you not be willing to talk to others?*
3. If you have a husband/partner/male family member, please tell me about how supportive they are of you getting preventative health services such as a Pap test.

4. **Has anyone ever made you feel afraid to get a Pap test?**  
*Probe: If yes, tell me who and/or why.*
5. **Do you know of any women that might be afraid to get a Pap test because of their husband or male family member?**
6. **What kinds of experiences have you had talking to the males in your life about getting a Pap test or about cervical cancer.**
7. **If you have not had any conversations about HPV, cervical cancer, or getting a Pap test, tell me some of the reasons that might keep you from talking about it.**
8. **What have you heard other members in your community say about getting a Pap test or about cervical cancer?**  
*Probe: Do people talk about it at all?*  
*Probe: What have you heard men say?*

### Part 3. Social Networks

---

For the next part of our conversation I will be asking you about some of the people that you are comfortable talking to. Please know that this information is just between you and I. You can also give me their initials if you don't feel comfortable telling me their first name.

1. **Please name up to 5 people you feel most comfortable talking about HEALTH ISSUES with.** *(you don't have to tell me their real names if you don't want to. You can give me their initials)*

Person 1: \_\_\_\_\_

Person 2: \_\_\_\_\_

Person 3: \_\_\_\_\_

Person 4: \_\_\_\_\_

Person 5: \_\_\_\_\_

☐ No one\*

***Interviewer:*** *write the names or initials that the participant gives you in the **name interpreter** and **network density** sections below.*

*\*Note: if they say no one, ask specifically if they don't have anyone or they don't want to name anyone. Reiterate that I **will not** be following up with or talking to the named people or trying to identify them in anyway. If they still do not wish to name anyone then this portion of the interview will be complete. Move on to Part 4.*

## Name interpreter questions

(This gets at the characteristics of the participants network and who they would trust getting information about cervical cancer prevention and characteristics of person who they wouldn't. This is important because it would help to identify who the opinion leaders are and who to target with information initially.)

**For the people that you just named, I would like to ask you a little bit more information about them. I will be asking you the same thing about each person so I will be repeating myself a lot.**

Person 1	Person 2	Person 3	Person 4	Person 5
_____	_____	_____	_____	_____

**Let's talk about the first person you named.** (*Repeat the same questions below for any other persons named above*)

**Is this person a male or a female?**

**What is their age?**

**How do you know this person?**

**How long have you known them?**

**How close do you live to them?**

**How often do you see this person?**

*Probe: Where do you see this person?*

**Do people tend to value this person's opinion on health matters?**

**Tell me about what (if anything) you and this person talk about related to cervical cancer or getting a Pap test.**

*Probe: you said that you don't talk about cervical cancer or a Pap test with this person.*

*Please tell me some reasons why.*

**Do you know if this person has gotten a pap test before?** (*if person named is a female*)

**Would you get a pap test if this person got one? (*if person named is a female*)**

**What would you do if this person thought you should not get a Pap test?**

**How much would you trust this person if they gave you information about HPV and/or cervical cancer?**

**{REMEMBER TO REPEAT THESE QUESTIONS FOR ALL THE PEOPLE NAMED  
BEFORE MOVING TO NEXT SECTION}**

### **Network density**

---

(It is important to look at this because of the close-knit nature of this community. This can speak to the characteristics of the network and whether density has anything to do with + or - attitudes toward cervical cancer prevention. It might also identify who has more influence in the network on the ego (individual).

**The next few questions will ask you if the people you named previously know each other (to the best of your knowledge).**

	<b>Person 2</b>	<b>Person 3</b>	<b>Person 4</b>	<b>Person 5</b>
	_____	_____	_____	_____
<b>Person 1</b>	Yes <input type="checkbox"/>	Yes <input type="checkbox"/>	Yes <input type="checkbox"/>	Yes <input type="checkbox"/>
	No <input type="checkbox"/>	No <input type="checkbox"/>	No <input type="checkbox"/>	No <input type="checkbox"/>
_____	Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>
<b>Person 2</b>		Yes <input type="checkbox"/>	Yes <input type="checkbox"/>	Yes <input type="checkbox"/>
		No <input type="checkbox"/>	No <input type="checkbox"/>	No <input type="checkbox"/>
_____		Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>
<b>Person 3</b>			Yes <input type="checkbox"/>	Yes <input type="checkbox"/>
			No <input type="checkbox"/>	No <input type="checkbox"/>
_____			Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>
<b>Person 4</b>				Yes <input type="checkbox"/>
				No <input type="checkbox"/>
_____				Not sure <input type="checkbox"/>

## Part 4. Health Communication Formats

---

**If you were to receive more information about HPV and cervical cancer, how would you like to receive the information?**

*Probes: radio, poster, from a trusted friend, doctor, etc.*

**Please tell me about other things that you would like to see or hear that would help you remember information about HPV, cervical cancer or getting a Pap test.**

*Probe: what about pictures?*

**Are there any other thoughts that you would like to share with me that we have not covered today?**

**Those are all the questions I have for your today. Thank you very much for your time!**

## Interview Guide and Social Network Questionnaire

(Men)

Location: \_\_\_\_\_ Date: \_\_\_\_\_ Start time: \_\_\_\_\_ End time: \_\_\_\_\_

Interviewer Initials: \_\_\_\_\_

### Introduction

#### **Interviewer script:**

*Hello! Thank you again for agreeing to talk with me today. My name is Venice Haynes, and this is Bethany Bateman and we are students at the University of South Carolina and University of Georgia in the United States. We will be working together during this interview to learn from you about the social relationships and the culture in Cusco as it relates to what men and women know about HPV and cervical cancer. We also want to ask for any suggestions you might have for the types of information you would like to see to get more education about the topic.*

*Taking part in this interview is completely voluntary, so please know that you can stop at any time if you do not feel comfortable continuing the conversation. You also do not have to answer any questions you don't feel comfortable answering. The interview will last about 45 minutes. I will be recording the conversation so that I capture everything that you say in your own words. I will not write or use your name in association with anything that you share with me today.*

*Are you still willing to participate in the interview?*

Consent to participate \_\_\_\_\_ (yes/no)

*Do you have any questions before we begin?*

*Great! Let's get started...*

**{TURN ON RECORDER}**



### **Demographic Questions**

**9. What is your language preference?**

- ☐ Spanish    How often? \_\_\_\_\_
- ☐ Quechua    How often? \_\_\_\_\_

**10. What is your age?**

Age \_\_\_\_\_

**11. Marital status?**

- ☐ Single
- ☐ Married
- ☐ Separated
- ☐ Widowed
- ☐ Divorced

**12. What is the highest level of education you have received?**

- ☐ No schooling
- ☐ Primary
- ☐ Secondary
- ☐ Undergraduate
- ☐ Graduate School
- ☐ Other

**13. Do you work?**

- ☐ Full-time
- ☐ Part-time
- ☐ Do not work
- ☐ Other

**14. Do you consider yourself and urban or rural resident?**

- ☐ Urban
- ☐ Rural
- ☐ Don't know

Thank you for this information. I will now begin with a few questions about what you know about HPV (human papillomavirus) and cervical cancer.

## Part 1. Knowledge about HPV and Cervical Cancer

---

1. Please tell me what you know (if anything) about HPV (human papillomavirus).
2. Please tell me what you know (if anything) about cervical cancer.  
*Probe: what do other men in the community know about cervical cancer?*
3. What do you think causes cervical cancer?
4. Please tell me what you know about a Pap test.
5. What do men in your community know about cervical cancer?  
*Probe: What do they know about HPV or a Pap test?*

**If male does not know about HPV, cervical cancer, or the purpose of a Pap test, please read the following note about it:**

*HPV is very common and is passed from one person to another during sexual activity. It is so common that nearly all sexually active men and women get it at some point in their lives and most of the time it clears on its own. When it doesn't clear in women, it can cause cervical cancer if she does not receive a Pap test regularly.*

*The Pap test (or Pap smear) looks for pre-cancers in women, which are cell changes on the cervix that might become cervical cancer if they are not treated appropriately. Cervical cancer is almost always caused by the human papillomavirus (HPV). Vaccines are available to protect against the types of HPV that most often cause cervical cancer.*

*The Pap test is recommended for women between ages 25 and 65 and can be done in a doctor's office or clinic. If the Pap test results are normal, the doctor may tell a woman to come back in 2-3 years to get the next Pap test. If a woman's results test results are normal, the chance of getting cervical cancer in the next few years is very low. Cervical cancer is highly preventable with regular Pap tests and follow-up care. It also can be cured when found early and treated.*

*{excerpt adapted from*

*<https://www.cdc.gov/cancer/dcpc/resources/features/cervicalcancer/index.htm>}*

**{If at a campaign site}**: please tell me what made you come out today.

*Probe: How did you hear about the CerviCusco services today?*

*Probe: tell me your thoughts about husbands supporting their wives getting a Pap test.*

**{If at the CerviCusco clinic}**: Please tell me what made you come into the clinic today.

*Probe: Tell me your thoughts about husbands supporting their wives getting a Pap test.*

**{If in the community}**: Go to Part 2

## **Part 2. Sociocultural influences**

---

I would like to switch our conversation a bit to talk about the females in your life and how supportive you are of their health.

**9. What have you heard members in your community say about getting a Pap test or about cervical cancer?**

*Probe: Do people talk about it at all?*

*Probe: What about men specifically?*

**10. Who in your community might be against women getting a Pap test?**

**11. What are some reasons a man might not want his wife/partner/female family member to get a Pap test?**

*Probe: Are there any preferences about who does the screening? Why or why not?*

**12. How supportive are you of your wife/partner/female family member getting a Pap test?**

**13. Do men typically want their wives to get screened or get treatment for cervical cancer?**

**14. If a woman received an abnormal Pap test result, and talked to her husband, how would he respond?**

*Probe: would he be angry, concerned, frustrated, calm?*

*Probe: would he blame the woman for having cervical cancer?*

**15. Please tell me about any experiences talking to the females in your life about getting a Pap test or cervical cancer.**

**16. If you have not had any conversations with the women in your life about a Pap test or cervical cancer, tell me about some of the reasons why you don't talk about it.**

**17. Please tell me about any times you have experienced someone you know having cervical cancer.**

*Probe: What were some of the emotions you experienced?*

18. Are there any groups in your community that oppose getting screened for cervical cancer?

19. How willing would you be to talk to others in your family or community about HPV or cervical cancer?

*Probe: Why or why would you not be willing to talk to others?*

### Part 3. Social Networks

---

For the next part of this interview I will be asking you about some of the people that you tell me you are comfortable talking to. Please know that I will not try to find these people or tell them about our conversation today. This information is just between you and I. You can also give me their initials if you don't feel comfortable telling me their first name.

2. Please name up to 5 people you feel most comfortable talking about health issues with. (you don't have to tell me their real names if you don't want to. You can give me their initials)

Person 1: \_\_\_\_\_

Person 2: \_\_\_\_\_

Person 3: \_\_\_\_\_

Person 4: \_\_\_\_\_

Person 5: \_\_\_\_\_

☐ No one\*

**Interviewer:**

write the names  
or initials that  
the participant  
gives you in the  
name interpreter  
and network  
density sections  
below.

*\*Note: if they say no one, ask specifically if they don't have anyone or they don't want to name anyone. Reiterate that I **will not** be following up with or talking to the named people or trying to identify them in anyway. If they still do not wish to name anyone then this portion of the interview will be complete. Move on to Part 4.*

### Name interpreter questions

(This gets at the characteristics of the participants network and who they would trust getting information about cervical cancer prevention and characteristics of person who they wouldn't. This is important because it would help to identify who the opinion leaders are and who to target with information initially.)

**For the people that you just named, I would like to ask you a little bit more information about them. I will be asking you the same thing about each person so I will be repeating myself a lot.**

**Person 1**

**Person 2**

**Person 3**

**Person 4**

**Person 5**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Let's talk about the first person you named. (*Repeat questions for any other persons named above*)**

**Is this person a male or a female?**

**What is their age?**

**How do you know this person?**

**How long have you known them?**

**How close do you live to them?**

**How often do you see this person?**

*Probe: Where do you see this person?*

**How much of a leader is this person in your community?**

*Probe: Do people tend to value this person's opinion on health matters?*

**Tell me about what (if anything) you and this person talk about related to cervical cancer.**

*Probe: you said that you don't talk about cervical cancer or a Pap test with this person.*

*Please tell me some reasons why.*

**Do you know if this person has gotten a Pap test before? (*if person named is a female*)**

**What would you do if this person disagreed with getting a Pap test? (*male or female*)**

**How much would you trust this person if they gave you information about HPV and/or cervical cancer?**

**{REMEMBER TO REPEAT THESE QUESTIONS FOR ALL THE PEOPLE NAMED  
BEFORE MOVING TO NEXT SECTION}**

## Network density

---

(It is important to look at this because of the close-knit nature of this community. This can speak to the characteristics of the network and whether density has anything to do with + or - attitudes toward cervical cancer prevention. It might also identify who has more influence in the network on the ego (individual)

**The next few questions will ask you if the people you named previously know each other (to the best of your knowledge).**

	Person 2	Person 3	Person 4	Person 5
	_____	_____	_____	_____
Person 1	Yes <input type="checkbox"/>	Yes <input type="checkbox"/>	Yes <input type="checkbox"/>	Yes <input type="checkbox"/>
	No <input type="checkbox"/>	No <input type="checkbox"/>	No <input type="checkbox"/>	No <input type="checkbox"/>
_____	Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>
Person 2		Yes <input type="checkbox"/>	Yes <input type="checkbox"/>	Yes <input type="checkbox"/>
		No <input type="checkbox"/>	No <input type="checkbox"/>	No <input type="checkbox"/>
_____		Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>
Person 3			Yes <input type="checkbox"/>	Yes <input type="checkbox"/>
			No <input type="checkbox"/>	No <input type="checkbox"/>
_____			Not sure <input type="checkbox"/>	Not sure <input type="checkbox"/>
Person 4				Yes <input type="checkbox"/>
				No <input type="checkbox"/>
_____				Not sure <input type="checkbox"/>

#### **Part 4. Health Communication Formats**

---

**If you were to receive more information about HPV and cervical cancer, how would you like to receive the information?**

*Probes: radio, pictures, poster, from a trusted friend, doctor, etc.*

**What kinds of information would you or other men need about cervical cancer prevention for the women in your life?**

**Are there any other thoughts that you would like to share with me that we have not covered today?**

**Those are all the questions I have for your today. Thank you very much for your time!**

## **Interview Guide**

**(Clinicians)**

**Location:** \_\_\_\_\_ **Date:** \_\_\_\_\_ **Start time:** \_\_\_\_\_ **End time:** \_\_\_\_\_

**Interviewer Initials:** \_\_\_\_\_

### **Introduction**

#### **Interviewer script:**

*Hello! Thank you again for agreeing to talk with me today. My name is Venice Haynes, and this is Bethany Bateman and we are students at the University of South Carolina and University of Georgia in the United States. We will be working together during this interview to learn from you about the social relationships and the culture in Cusco as it relates to what men and women know about HPV and cervical cancer. We also want to ask for any suggestions you might have for the types of information you would like to see to get more education about the topic. You have been selected to participate in this interview because you are affiliated with a clinic that provides Pap smears and HPV vaccinations to Peruvian women.*

*Taking part in this interview is completely voluntary, so please know that you can stop at any time if you do not feel comfortable continuing the conversation. You also do not have to answer any questions you don't feel comfortable answering. The interview will last about 45 minutes. I will be recording the conversation so that I capture everything that you say in your own words. I will not write or use your name in association with anything that you share with me today.*

*Are you still willing to participate in the interview?*

Consent to participate \_\_\_\_\_ (yes/no)

*Do you have any questions before we begin?*

*Great! Let's get started...*



## **Patient Demographic Questions**

1. What is your language preference?  
☐ Spanish    How often? \_\_\_\_\_  
☐ Quechua    How often? \_\_\_\_\_
2. Do most of your patients speak Spanish or Quechua primarily?
3. What is the demographic of your patients?
  - Education
  - Marital status
  - Work status
  - Income
4. How many Pap test do you perform on a weekly basis?
5. How many patients do you see that are getting a Pap test for the first time?
6. How old are women on average when they get their first Pap test?

Thank you for this information. I will now begin with a few questions about what your patients know about HPV (human papillomavirus) and cervical cancer.

## **Part 1. Knowledge about HPV and Cervical Cancer**

7. What do your patients know about HPV (human papillomavirus)?
8. What do they know about cervical cancer?
9. What do your patients think causes cervical cancer?
10. Why do they think a Pap test is done?
11. How do they hear about the CerviCusco services?

- 12. If any of your patients have had at least one Pap test before, what types of experiences have they shared with you about their last Pap test (if any)?**
- 13. Tell me about your patient's reactions to needing follow-up care including any reasons as to why they don't come back.**

## **Part 2. Sociocultural influences**

---

I would like to switch our discussion a bit to talk about the males and how supportive they are of women's health.

- 14. Please tell me about any experiences you may have had with your patients feeling ashamed or embarrassed getting a Papanicolaou?**  
*Probe: Do they mention anyone specifically who make them feel that way?*
- 15. What roles have you seen husbands/partners/male family members play in women getting Pap tests?**
- 16. What myths have you heard related to cervical cancer and Pap test?**
- 17. What kinds of issues come up with women who need treatment for cervical cancer?**
- 18. How common is it for men and women to talk openly about HPV and/or cervical cancer?**  
*Probe: what might be some reasons for this?*
- 19. How supportive are men in their wives/family members getting treatment?**
- 20. How have males reacted to their wives or family members being diagnosed with cervical cancer?**  
*Probe: What are some reasons why men would not want them to get treated?*
- 21. Who do women tend to consult with about getting a Pap test or treatment for cervical cancer?**  
*Probe: husbands, family members, friends?*

## **Part 3. Social Networks and Health Communication Formats**

---

- 22. Who do women tend to feel the most comfortable talking about health issues with?**
- 23. Based on your conversations with your patients, do women tend to get a Pap test if their friend or family gets one or do they make the decision on their own?**

24. Who do men and women tend to trust information from regarding HPV and cervical cancer?
25. What kinds of information do you think is important for men to receive about HPV and cervical cancer?
26. What kind of information do you think is important for women to receive about HPV and cervical cancer?
27. What would be the best way to deliver the information? (i.e. radio, poster, from a trusted friend, doctor, etc.)

Are there any other thoughts that you would like to share with me that we have not covered today?

Those are all of the questions I have for your today. Thank you very much for your time and participation!

APPENDIX B  
CONSENT FORM

**Title:** Exploring sociocultural influences on cervical cancer prevention and control behaviors in Cusco, Peru

**Principal Investigators:** Venice E. Haynes, MSPH, Heather M. Brandt, PhD, CHES

**Address:** University of South Carolina  
Cancer Prevention and Control Program  
915 Greene St., Suite 200  
Columbia, South Carolina 29208  
U.S.A.  
+1 803 777-7641

**PURPOSE:**

You are being asked to volunteer for a research study conducted by Venice Haynes, a doctoral student in the Department of Health Promotion, Education and Behavior in the Arnold School of Public Health at the University of South Carolina in the United States. The purpose of this study is to explore factors in your social environment to better understand the role your social environment has on knowledge and attitudes about HPV and cervical cancer. You are being asked to take part in this study because it will help to identify way to educate the community and lower cervical cancer in areas across Cusco, Peru. Additionally, findings from this study will be used to inform culturally tailored health communication campaigns to educate Peruvian men and women in urban and rural areas about cervical cancer causes, screening, and prevention. This study is being done at different sites across Cusco and will involve approximately 45 volunteers. This form explains what you will be asked to do if you decide to take part in this study. Please read this form carefully and feel free to ask questions before you make a choice about taking part. If you have any questions, please contact:

Venice Haynes at +1 803 777-7641 (U.S.); (51) 84-273453 (Peru) or [vehaynes@email.sc.edu](mailto:vehaynes@email.sc.edu)

Dr. Heather Brandt at +1 803 576-5649 or [hbrandt@sc.edu](mailto:hbrandt@sc.edu)

**PROCEDURES:**

You have been asked to take part in the study because you are a Peruvian male or female or healthcare provider, are at least 25-years of age, and are eligible or have a female family member who is eligible to receive a Pap test, or you provide Pap test for eligible women.

If you agree to be in this study, I will ask you to do the following:

1. Take part in a one-time, 45-minute interview that will ask you about your knowledge about cervical cancer and HPV, what you have heard are causes of cervical cancer, experiences with receiving a Pap test (if applicable), the support you receive from male partners or family members, and who you talk to on a regular basis that you feel comfortable talking about cervical cancer and HPV. We will also ask you about how you would like to receive information about the disease, or if you are a healthcare provider, what information you think would help your patients. I will audio record our discussion to ensure I capture the details that you provide. Your name will not be associated with anything that you say.

**DURATION:**

Participation in the study will take one (1) visit over a period of one (1) day. Each interview will last about 45 minutes.

**RISKS/DISCOMFORTS:**

Minimal risks are expected because of participating in the study. Your participation is completely voluntary. If you decide you do not want to be in this study at any time, it will not affect your care at CerviCusco or any other clinic. Risks to confidentiality are small. Your information will be identified with a study ID, not your name or other identifiable information. Study IDs and participant names will be kept in separate locations. All hard copy data will be kept in a locked cabinet. Electronic data will not contain any names and will be kept in a secure password protected database.

**BENEFITS:**

There may or may not be direct benefits to participation in this study. If you choose to take part in this study, it could lead to an improved understanding of HPV and cervical cancer and your participation will potentially contribute to a tailored health communication campaign to improve cervical cancer rates in your community.

**COSTS/ PAYMENT TO PARTICIPANTS:**

There will be no cost to you for participating in the study. You will receive S/.20 (Peruvian soles) for participating in the interview.

**ALTERNATIVES:**

You have the choice to take part in this study or not. If you decide not to take part, you would not have to do any of the things listed above. If you begin the study, you have the right to withdraw from the study at any time without negative consequences.

**CONFIDENTIALITY OF RECORDS:**

Any information that is obtained in connection with this study will remain confidential and will be disclosed only with your expressed written permission, unless required by

law. The information will be securely stored in locked files and on password protected computers. The results of the study may be published or presented at seminars, but the report **will not** include your name or other identifying information about you.

### **QUESTIONS:**

You may contact Venice Haynes or Dr. Heather Brandt if you want to learn more about the study and benefits of participating. This study has been approved by the University of South Carolina Institutional Review Board which is a committee that reviews research to make sure that those that participate will be treated ethically. You can get more information about your rights as a research participant by calling the Office of Research Compliance of the University of South Carolina at +1 803 777-7095.

*I have been given a chance to ask questions about this research study. These questions have been answered to my satisfaction. If I have any more questions about my participation in this study, I may contact Venice Haynes at +(51) 84-273453 or email at [vehaynes@email.sc.edu](mailto:vehaynes@email.sc.edu).*

*If I have any questions, problems, or concerns, desire further information or wish to offer input, I may contact Lisa Marie Johnson, IRB Manager, Office of Research Compliance, University of South Carolina, 1600 Hampton Street, Suite 414D, Columbia, SC 29208, phone: +1 (803) 777-7095 or email: [LisaJ@mailbox.sc.edu](mailto:LisaJ@mailbox.sc.edu). This includes any questions about my rights as a research subject in this study.*

*I agree to take part in this study. I have been given a copy of this form for my own records.*

*If you wish to participate, please sign below.*

_____	_____	_____	_____
<b>Print Name of Participant</b>	<b>Date</b>	<b>Signature of Participant</b>	<b>Date</b>
_____	_____		
<b>Signature of Person Obtaining Consent</b>	<b>Date</b>		

APPENDIX C  
USC IRB APPROVAL LETTER





OFFICE OF RESEARCH COMPLIANCE

INSTITUTIONAL REVIEW BOARD FOR HUMAN RESEARCH  
APPROVAL LETTER for EXEMPT REVIEW

Venice Haynes  
Arnold School of Public Health  
Health Promotion, Education & Behavior  
915 Greene Street, Rm 529  
Columbia, SC 29208

Re: **Pro00076867**

Dear Ms. Haynes:

This is to certify that the research study ***Sociocultural Influences on Cervical Cancer Prevention and Control Behaviors in Cusco, Peru*** was reviewed in accordance with 45 CFR 46.101(b)(2), the study received an exemption from Human Research Subject Regulations on **3/22/2018**. No further action or Institutional Review Board (IRB) oversight is required, as long as the study remains the same. However, the Principal Investigator must inform the Office of Research Compliance of any changes in procedures involving human subjects. Changes to the current research study could result in a reclassification of the study and further review by the IRB.

Because this study was determined to be exempt from further IRB oversight, consent document(s), if applicable, are not stamped with an expiration date.

All research related records are to be retained for at least three (3) years after termination of the study.

The Office of Research Compliance is an administrative office that supports the University of South Carolina Institutional Review Board (USC IRB). If you have questions, contact Arlene McWhorter at [arlenem@sc.edu](mailto:arlenem@sc.edu) or (803) 777-7095.

Sincerely,

Lisa M. Johnson  
ORC Assistant Director  
and IRB Manager

APPENDIX D

PERUVIAN IRB APPROVAL LETTER



Lima, 19 de Junio del 2018  
CE1050.18

Carlos Gonzales 251  
San Miguel 15088  
Lima - Perú  
T 511 209 0400  
prisma.org.pe

**cambiamos vidas  
cambiamos el mundo**

Licenciada  
**Venice E. Haynes, MSPH**  
Investigador Principal  
Universidad de Carolina del Sur  
Escuela de Salud Pública Arnold  
Presente.-

**Ref: Protocolo titulado: "Explorando los factores socioculturales de la prevención del cáncer cervical y los comportamientos del control en Cusco, Perú"**

De nuestra consideración:

Es grato dirigirnos a usted a fin de informarle que el Comité de Etica ha revisado los cambios sugeridos y procede con la **APROBACION** de los siguientes documentos del estudio en mención:

- **IRB Protocolo, Versión 2: 6 junio 2018**
- **Consentimiento Informado al Participante de la Investigación, Versión 3: 7 junio, 2018**

Sin otro particular por el momento, nos despedimos de Usted.

Atentamente

Salomón Zavala Sarrio  
Presidente  
Comité Institucional de Etica en Investigación

APPENDIX E  
CODEBOOK

Domain (Category)	Dimension (Sub-Category)	Second Sub-Category	Definition
<b>Knowledge</b>	---	---	Participants responses to questions about what they know about HPV, the Pap test, and cervical cancer (cxca)
	<b>Knowledge about HPV</b>		What participants say they know about the human papillomavirus
	<b>Knowledge about Pap test</b>	---	What participants know about the Pap test
	<b>Knowledge about cxca</b>		What participants think the Pap test is for
		What men know about the Pap test and cervical cancer	
<b>Cultural beliefs</b>	---	---	Anything the participant reports related to what they or others in the community say about getting a Pap test or cervical cancer, good or bad.
	<b>Embarrassment/shame</b>		Shame associated with getting a Pap test or having the disease
	<b>Fear</b>		Participants accounts of someone shaming them or making them afraid to get a Pap test
	<b>Causes of Cxca</b>		What participants think causes cervical cancer
	<b>Community conversations about the Pap test and Cxca</b>		What participants say they've heard in the community about Pap tests and/or cxca.
		Stigma	How participants describe cxca as a disgraced topic or disease

		Community members against Pap test	Who in the community has something negative to say about the Pap test
	<b>Willingness to talk about cxca</b>		How likely the participant is to talk to others about the topic
		Reasons for not talking about CxCa	Reasons participants say they don't talk about HPV or cervical cancer
	<b>Gender ideologies</b>		The dynamic between men and women in their culture that might indicate machista or marianismo ideologies
		Spousal/partner support	The support of men for their wives or partners to get a Pap test
		Spousal fear	Participants indicating that they or someone they know is afraid to get a Pap test because of their husband
		Talking with spouse about Cxca	Participant accounts of conversations (or lack thereof) about the topic and why
		Machista/machismo	References to the male gender ideology that he exercises control over a woman as it relates to getting a Pap test
		Marianismo	References to the female gender ideology as the submissiveness and subservient attitude of a woman toward their male partner as it relates to getting a Pap test
		Men's attitudes about the Pap test and cxca	Men's comments or women's accounts of how men treat the conversation about the Pap test or cervical cancer
		Gender preference for exam	Preference of participants for who administers the exam (male or female)

<b>Health communication</b>	---	---	Preferences for how participants wanted health information, who from, what information they would need, and other comments related to communicating information about cxca
	<b>Preferred channels</b>		Preferences participants mention for receiving health information (i.e. radio, friends, doctor, etc.)
		Radio	
		TV	
		Video	
		Posters	
		Written materials	
		Trainings and workshops	
		Internet and social media	
	<b>Interpersonal communication</b>		Face to face, or one-on-one conversations with another person, doctor, nurse, etc.
		Doctor or professional	Clinician, gynecologist, specialist that knows about Pap tests and cervical cancer
		Family member or friend	Persons participants would like to receive health information from outside of a doctor or clinician